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ABSTRACT

Nine year 2000 issues of the newsletter of TASH, formerly The Association for Persons with Severe Handicaps, comprise this document. Each issue typically contains news items, a column by the organization's executive director, reports from special interest groups, legislative testimony, conference information, and several major articles relating to equity, quality and social justice for people with disabilities. The February/March 2000 through December 2000/January 2001 issues address: (1) 1999 TASH conference highlights, including excerpts from keynote addresses by Rich Villa and Kyle Glozier, and Inclusion and Universal Cooperation (Rosangela Berman Bieler); (2) inclusive schooling, with articles such as Including Students with Disabilities in Standards Based Education Reform (Kathy Boundy), Collaboration at Whittier High School (Mary Falvey and others), Whole Schooling: Linking Inclusive Education to School Renewal (Michael Peterson), The Inclusion of a Youth with Significant Disabilities in a Community Environment (Teri Jasman and others), and Reinventing Community in the Age of Globalization (Wayne Sailor); (3) embracing sexuality, which includes articles such as Moving beyond Denial, Suppression and Fear to Embracing the Sexuality of People with Disabilities (Pamela S. Wolfe and Wanda J. Blanchett), But I Thought Sexuality and Teens with Developmental Disabilities (Dave Hingsburger and others), Absence of Evidence: Myths about Autism and Mental Retardation (Anne Donnellan); (4) issues in supported employment, which includes Are We There Yet? Trends in Employment Opportunities and Supports (John Butterworth and Dana Gilmore), The Ticket-to-Work and Supported Employment: How Will It Work? (Dan O'Brien), and "Systems Change and Supported Employment: Is There Empirical Evidence of Change? (David Mank); (5) the victimization of people with developmental disabilities in the criminal justice system, which includes Doing Justice: Criminal Offenders with Developmental Disabilities (Joan Petersilia), Serious Issues Facing Today's Offender with Mental Retardation (Leigh Ann Davis), and

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Violence against Women with Developmental Disabilities: The Hidden Violence (Catriona Johnson); (6) the agenda and workshop descriptions for the 2000 TASH conference; (7) international perspectives, which includes Providing AAC Systems for Children in a Guatemalan Orphanage: How Do We Help Others in Culturally Responsive Ways? (Janet M. Duncan), Mental Health, Mental Retardation and Protection of Rights under International Law (Mental Disability Rights International), and New Voices in Iceland: Growing Up with a Disability (Dora S. Bjarnason); (8) early childhood, which includes Variables that Contribute to Self-Determination in Early Childhood (Elizabeth J. Erwin and Fredda Brown), What Children and Families Need in Health Care from Birth through Adulthood: One Parents Experiences and Advice (Kris Schoeller), Re-thinking Guardianship (Dohn Hoyle and Kathleen Harris), and Increasing Childrens Learning Opportunities in the Context of Family and Community Life (Carl J. Dunst and Mary Beth Bruder); and (9) highlights from the 2000 TASH conference. (CR)

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TASH Newsletter

Priscilla Newton, Editor

Volumes 26 - 27
Numbers 2/3 - 12/1
Feb/Mar 2000 - Dec 2000/Jan 2001

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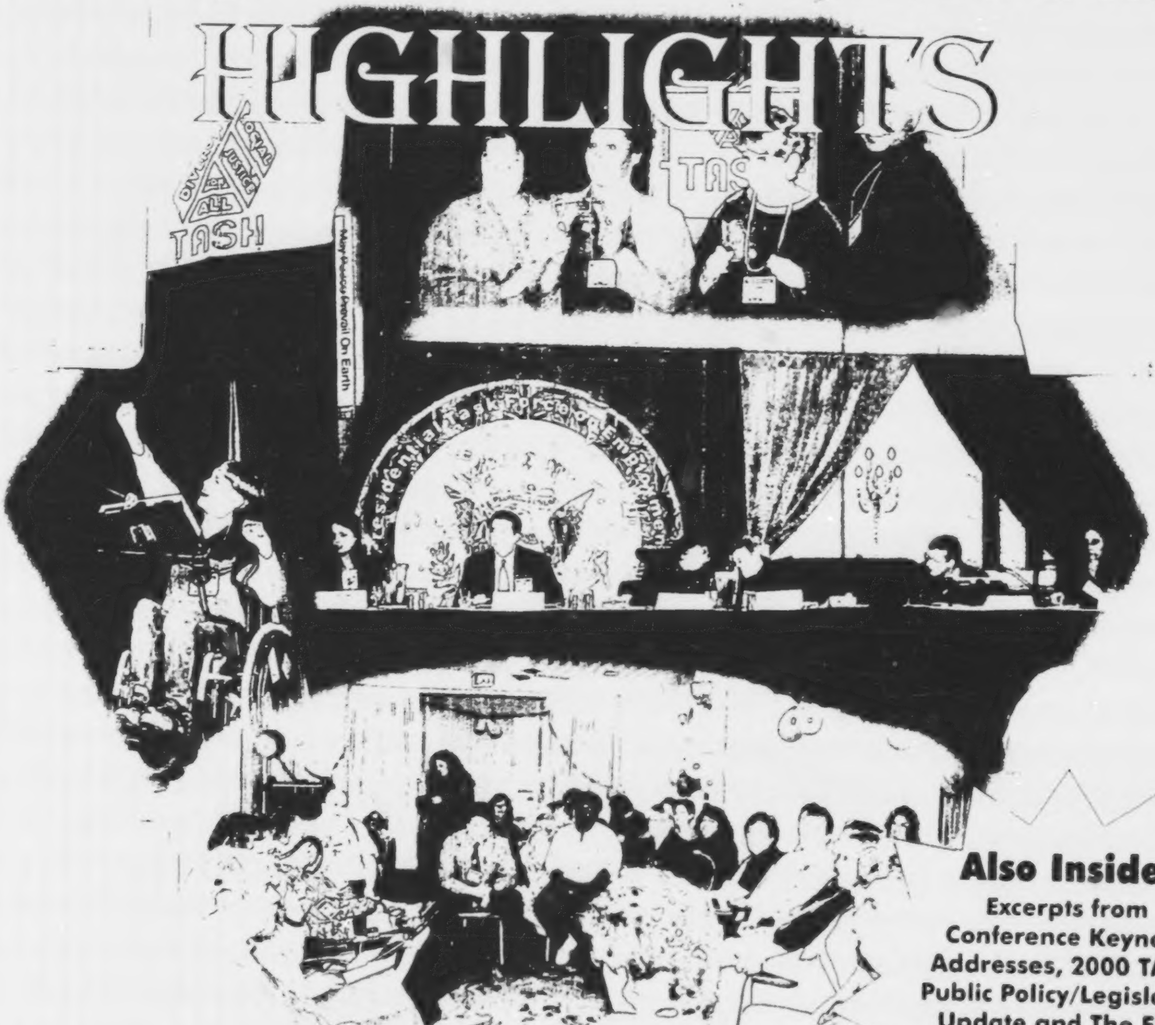
TASH Newsletter

VOLUME 26 ISSUE NUMBER 2/3 FEBRUARY/MARCH 2000

1999 CONFERENCE HIGHLIGHTS


DIVERSITY
JUSTICE
EQUAL
ALL
TASH!
TASH
May Justice Prevail On Earth

Also Inside:

Excerpts from Conference Keynote Addresses, 2000 TASH Public Policy/Legislative Update and The First International Conference on Self-Determination and Individualized Funding

2000 Calendar of TASH Chapter and Member-Sponsored Conferences

May 2000

"Crossing dis/Ability Borders: Beyond the Myth of Normal" - Facilitated Communication Institute Annual Conference

May 1-2

Preconference Day - April 30, 2000

Sheraton University Hotel and Conference Center, Syracuse University

Further information about the conference is available on the FC Institute web site, http://soeweb.syr.edu/thefci

"Pioneer Spirit - Blazing New Trails" International Parent to Parent Conference 2000

May 5-7, 2000

Reno, Nevada.

Host: Nevada University Affiliated Programs

Phone: (775) 784-4921

FAX: (775) 784-4997

"13th Annual Issues on Aging Conference"

May 15-17 (May 17 will focus on Aging and Developmental Disabilities)

Wayne State University, Institute of Gerontology

Troy, Michigan

For more information, call (313) 577-1180

E-mail: jfreytag@med.wayne.edu

Web site: www.iog.wayne.edu

Italy Seminar - "Education in Italy: An Inclusive Approach"

May 16-June 11

Site visits to schools in Rome, Florence, Parma, and a rural village near Naples.

Contact: Dr. Carol Berrigan, Seminar Director, Syracuse University

Phone: 315-443-3851

E-mail: crberrig@syr.edu

July 2000

"The Toronto Summer Institute on Inclusion, Community and Diversity"

Originally scheduled for July 8-14, 2000 in Toronto, Canada, has been postponed until July 2001.

First International Conference on Individualized Funding & Self-Determination

July 29 - 31, 2000

Westin Seattle Hotel, Seattle, Washington

For additional information on registration, sponsorship, or scholarships, contact Denise Marshall, TASH, 410-828-8274, ext. 103 or E-mail dmarsh@tash.org

"15th Annual Early Intervention and Early Childhood Summer Institute"

July 31 - August 4

Williamsburg, Virginia

Co-sponsored by Child Development Resources and the College of William and Mary School of Education

For more information contact Lisa McKean, Phone: (757) 566-3300

Fax: (757) 566-8977

E-mail: lisam@cdr.org

December 2000 — Annual TASH Conference

December 6-9

Miami, Florida

The Fontainbleau Hilton Resort & Towers

December 6, 2000 - Pre-Conference Workshops & Opening Reception

December 7 - 9, 2000 Annual TASH Conference

To have your event or conference added to our web site please send information to Denise Marshall at dmarsh@tash.org or fax to 410-828-6706.

ARE YOU A UNIVERSITY PROFESSOR? TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2000 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Dan Dotson, Coordinator of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:ddotson@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions and advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

TASH WISHES TO ACKNOWLEDGE THE GENEROUS SUPPORT OF OUR NEWEST LIFETIME MEMBERS

MICHAEL CALLAHAN - GAUTIER, MISSISSIPPI

PAT EDWARDS - SHELBY, OHIO

KATE MCCOY - BLACKSBURG, VIRGINIA

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.

From the Executive Director

BY NANCY WEISS

Annually, the TASH Executive Board completes a strategic planning process that results in goals for the upcoming year. This year the Board created a lengthy list of possible priorities well before their annual meeting in Chicago and sent these out to committee chairs and chapter representatives for input. In addition, committee chairs were invited to the Board meeting in Chicago to comment on their committees' priorities and recommendations for organization-wide activities and goals.

This year's priorities are listed below. In addition, the Board member responsible for drafting and implementing an action plan for each priority is indicated. Board members are in the process of designing action plans and they welcome member involvement. If you have particular interest in any of these priorities and would like to work with TASH toward affecting meaningful change in these areas, we welcome your participation. Please contact the Board member indicated for each priority.

TASH Priorities 2000

Advocacy-Related Priorities

1. Collaborate/build support and connections with general educators, minority members of congress, and other social justice organizations.
   Board member to contact (see contact information to the right): Donna Gilles
2. Work to make sure that people have meaningful employment and living opportunities
   Board member to contact (see contact information to the right): Liz Obermayer
3. Strengthen the voice of people labeled severely disabled
   Board member to contact (see contact information to the right): Doug Biklen
4. Promote inclusion within higher education
   Board member to contact (see contact information to the right): Liz Healey
5. Work toward closing institutions and other segregated living and work settings
   Board member to contact (see contact information to the right): Liz Obermayer
6. Enforce IDEA
   Board member to contact (see contact information to the right): Jorge Pineda
7. Promote passage of MiCASSA
   Board member to contact (see contact information to the right): Joe Wykowski

Operations-Related Priorities

1. Maintain capacity for legislative advocacy
   Board member to contact (see contact information to the right): Donna Gilles
2. Develop working relationships with committees to assure committees have the support needed to accomplish tasks
   Board member to contact (see contact information to the right): Liz Obermayer
3. Fiscal development
   Board member to contact (*see contact information to the right*): *Joe Wykowski*
4. Increase membership
   Board member to contact (see contact information to the right): Jorge Pineda
5. Support the development and promotion of an electronic journal
   Board member to contact (see contact information to the right): Doug Biklen
6. Improve relations with and support of chapters
   Board member to contact (see contact information to the right): Liz Healey

Contact numbers for board members working on priority activities:

▽ ▽ ▽

Doug Biklen
Phone: 315-443-9218
E-mail: dpbiklen@syr.edu

Donna Gilles
Phone: 352-846-2760
E-mail: gilles@ufbi.ufl.edu

Liz Healey
E-mail: healeylz@aol.com

Liz Obermayer
Phone: 410-583-0060
E-mail: LizObe@aol.com

Jorge Pineda
Phone: 703-525-3406
E-mail:
JorgeandJudith@compuserve.com

Joe Wykowski
Phone: 503-292-4964, ext. 101
E-mail:
74452.3365@compuserve.com

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TASH Public Policy/Legislative Update

BY DAN DOTSON, COORDINATOR, GOVERNMENTAL AFFAIRS

TASH's new Coordinator of Governmental Affairs, Dan Dotson, will provide members with regular updates from the governmental affairs and public policy arena. If you have questions about specific activities, or would like to become involved in TASH's governmental affairs committee, please contact Dan at 410-828-8274, ext. 104 or <ddotson@tash.org>

IDEA Enforcement

On January 25, 2000, Marca Bristo, Chairperson of the National Council on Disability, announced the release of a new report, *Back to School on Civil Rights: Advancing the Federal Commitment to Leave No Child Behind.* In its report NCD found that the leadership and enforcement of IDEA by the current and past administrations has been "inconsistent and ineffective." Even after 25 years of Federal law guaranteeing the basic right to an appropriate education, parents and families are too often burdened with the responsibility of enforcement of the law at great expense to their families, careers and financial security. Federal efforts to ensure local compliance of Part B of IDEA have been just as ineffective.

The report makes recommendations to the President and to Congress on how to strengthen and build on the 1997 IDEA Reauthorization Act. TASH will continue to work with other disability rights groups, the Administration and Congress, to ensure that the issues identified in the report are addressed to produce stronger federal enforcement that will ensure compliance. To read the full text of the report go to: http://www.ncd.gov/publications/backtoschool_1.html

MiCASSA Update

The Medicaid Community Attendant Services and Supports Act (MiCASSA) was introduced in Congress by Senator Tom Harkin (D-IA) and Senator Arlen Spector (R-PA) as Senate Bill 1935. MiCASSA's goal is to provide flexible, consumer-responsive services directed by the individual receiving the services. In short, MiCASSA will allow for consumer control of how, when, where and by whom services are delivered.

At the 1999 TASH Conference, TASH identified the passage of MiCASSA as one of its legislative priorities for the coming year. TASH will monitor this bill closely as it moves through Congress and keep its members informed of the bill's progress. As MiCASSA is ushered through Congress, TASH will be working along with other organizations to see that the true voice of the grassroots disability community is heard.

For more information about MiCASSA, please contact ADAPT at www.adapt.org or Dan Dotson, TASH, at 410-828-8274 x104 or ddotson@tash.org.

New TASH ListServe

TASH has set up a new listserve community to serve as a forum for TASH members and supporters to discuss the issues affecting people with disabilities. This new listserve will provide members and other interested persons with an opportunity to identify and connect with others who share particular interests, expertise, and experiences.

TASH will use the list to keep users up to date on upcoming events, future articles, conference information, legislative action and discussions of current events. Other lists may be spun-off on more specific topics as the list grows.

To subscribe to the list, send a blank email to: TASHUpdate-subscribe@onelist.com or got to http://www.onelist.com/group/TASHUpdate. See you online!

Constitutionality of the ADA

Adapted from an article by Sharon Masling of National Association of Protection and Advocacy Systems, (NAPAS).

A Real Threat: Supreme Court May Declare Title II of the ADA Unconstitutional

The Supreme Court had decided to hear two disability discrimination cases — *Florida Department of Corrections v. Dickson* and *Alsbrook v. City of Maumelle* — both of which involved questions about the constitutionality of Title II of the ADA. Fortunately, both of these cases have been settled and will not be moving forward. However, there are other cases looming on the horizon that could have a major impact on the civil rights of people with disabilities.

At issue is whether Congress had the constitutional authority under the Fourteenth Amendment to enact the ADA. If the Supreme Court says Congress did not, indi-

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TASH Public Policy/Legislative Update

Continued from page 5

viduals may no longer be able to enforce the ADA at the state level. More importantly, a negative ruling could call into question the constitutionality of Title II of the ADA as well as other disability rights statutes.

Dickson and *Alsbrook* are the latest in a series of cases in which states have challenged Congress' power to enact legislation regulating state conduct. Most recently, the Supreme Court held in *Kimel v. Florida Board of Regents* that Congress did not have the authority to apply the Age Discrimination in Employment Act to the states.

What does this mean for people with disabilities? If the Court finds as it did in the *Kimel* case, states may no longer be subject to the ADA's requirements. Depending on the scope of the Supreme Court's future rulings:

- States may no longer have to comply with the ADA's integration mandate. People who are unneccessarily institutionalized in state hospitals, nursing homes, and other state institutions may no longer have recourse under the ADA.
- States may no longer have to make their buildings and services accessible. State capitols, state courts, and state universities, among others, may no longer have to have wheelchair ramps, provide interpreter services, or provide written materials in accessible formats.
- State employers may no longer have to comply with the ADA's mandate against employment discrimination. State employers may be able to refuse to hire and/or fire people with disabilities at will, and may no longer have to provide employees with disabilities-reasonable accommodations in the workplace.

While the cases currently before the Supreme Court only address the applicability of the ADA to the states, a negative decision could lead to the Court striking down Title II of the ADA altogether. We are at risk of losing not only Title II as it applies to the states, but as it applies to all public entities.

People with disabilities worked too long and too hard to enact the ADA only to see it succumb to a "states' rights" argument. As they did in *Olmstead v. L.C.*, disability rights advocates can make a difference. States will undoubtedly file a brief with the Supreme Court, urging the Court to find that the ADA does not apply to them. Here's what you can do to counter the impact of that brief:

Here's How You Can Help

- Educate disability rights advocates in your state that the threat to the ADA is real and the time to act is now. The states' brief was due on March 3 in *Dickson* and is due on March 31 in *Alsbrook*.
- Work in conjunction with other disability rights advocates in your state. Coalitions formed around *Olmstead v. L.C.* are a great place to start.
- Determine the best way to approach your state. Approach your governor, attorney general, state legislators, mental health and developmental disability directors, and other state officials with whom you have relationships, including civil rights enforcement attorneys in the state attorney general's office.
- Ask your state to sign on to a brief supporting the constitutionality of the ADA. Explain how important the ADA is to you, how the law has had a direct impact on your life, and how dismayed you are by the thought that your state would take the position that it should not have to comply with the law's requirements.
- If your state will not sign on to a brief supporting the ADA, ask your state officials to not sign on to the "state's rights" brief. It will send a powerful message to the Court if only a handful of states argue that the ADA should not apply to them.
- Do not be dissuaded by the fact that your state already may have challenged the constitutionality of the ADA in pending litigation. Governors and other state officials may be unaware and unsupportive of the litigation positions previously taken by their state attorney generals, and may be able to influence the position taken by your state in *Dickson* and *Alsbrook*.
- Take advantage of any promises made during your advocacy around the *Olmstead v. L.C* case. In many discussions around *Olmstead*, advocates were assured that they would be consulted in the future concerning similar matters. Make use of those commitments now.

Secure a commitment from your state to continue meeting and working on disability rights issues. Even if your state signs on to a brief opposing the constitutionality of the ADA, all is not lost. Your state may feel compelled to sign on to a brief because of larger "state's rights" issues. If that happens, try to secure a commitment from your governor and attorney general that they will continue to meet and work with you on issues affecting the rights of people with disabilities in your state.

Summer Institute

2nd Annual

NH's Summer Institute on Supporting Students with Autism/PDD in General Education Classes

Save the Date ▪ June 26 - June 29, 2000
Manchester ▪ New Hampshire

This four day summer institute will provide participants with state-of-the-art information and strategies in the area of educating students with autism/PDD in general education classes. Each morning participants will hear a keynote presentation from a national leader in the field of autism. In the afternoon, working in small groups, participants will synthesize this new information and develop strategies for supporting students with autism/PDD in their schools and families.

KEYNOTE PRESENTERS:

Temple Graydin, Thinking in Pictures: My Life with Autism ▪ *Rae Sonnenmeier and Michael McSheehan*, Supporting Communication with Students with Autism/PDD: It's About Building Relationships ▪ *Gail Gillingham*, Autism: The Impact of Expectations and Fears ▪ *Carol Gray*, From Both Sides Now: How to Teach Social Understanding

REGISTRATION INFORMATION

Individual Registration Rate: $300/person
Team Rate (3 or more registrations): $275/person

For information, please call Deb Wilkinson at 603-228-2084 or 800-238-2048.
Visit us on the web: http://iod.unh.edu

EXCERPTS FROM 1999 KEYNOTE ADDRESS: RICH VILLA

The Future of Education

I am honored to have an opportunity to speak to you this morning. I am also a bit humbled by this invitation. Much of what I know about education, social justice, and inclusion has been taught to me by the members of this organization — through your writing, your teaching, your advocacy, and through your modeling. I was asked to speak to you about the possible future of education. I concluded, however, that I had to speak instead about the possible futures of education. The future is not certain. It is the actions that we take that will determine the future in which our children and we will live. I speak of the children that are members of our families, as well as the children for whom we have the responsibility to educate. As Carl Sandburg said, *"There is only one child in the world and that child's name is All children."*

I agree with the noted anthropologist, Margaret Mead, who said, *"We are now at a point where we must educate our children in what no one knew yesterday and prepare our schools for what no one knows yet."* In thinking about the future, I had to think about the present and I had to reflect on the past because, as educational historian Frank Rippa tells us, *"There is a considerable advantage in trying to understand the current situation through a historical perspective."* Blakenship and Lilly also remind us that *"through practically all of the history of civilization, education has been for the elite, and educational practices have reflected an elitist orientation."* Yet, there have always been visionaries, including many of the members of this organization, whose thinking was ahead of their time and place in history.

Nearly five hundred years ago, Comenius, the founder of Charles University, the second oldest university in Europe, had a vision about education. Comenius stated, *"Education should be available not just to one man or a few or even to many men, but to all people together as well as to each separately. Young and old, rich and poor, irrespective of birth, men and women — in short, everyone — whose fate it is to have been born a human being."*

In preparing for this keynote, I thought about the challenges that face teachers as they enter the first century of the new millennium. I also thought about the challenges that faced teachers 100 years ago as they entered the 20th century. Tomorrow's teachers face the same challenges that a teacher in a one-room schoolhouse faced at the turn of the last century. The challenge remains the same — how to reach out to students who span the spectrum of learning readiness, personal interest, culturally shaped ways of seeing and speaking, and who have had various experiences in the world. As we enter this century we have greater diversity within our schools in terms of culture, language, and perception of ability, gifts, and talents than we did at the start of the last century. However, the basic challenge remains the same. Gerlach reminds educators, *"Our task is to provide an education for the kinds of kids we have, not the kinds of kids we used to have, want to have, or the kids that exist in our dreams."*

◆

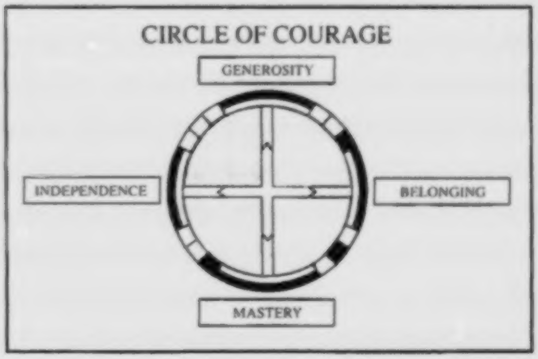
There is, however, a danger to any society that over-emphasizes academics at the cost or expense of social and life skills. "Reading, writing, and arithmetic are important only if they serve to make our children more humane."

◆

Please think about the following questions. "What is the dream that we have for our students? What are the desired goals or outcomes of education? What are the skills, competencies, talents, attributes, and dispositions that our students are going to need to lead quality lives in the future?" I'd like you to reflect on these questions for a moment and then to turn to someone who is sitting near you and share the skills, competencies, talents, and attributes that you identified.

Circle of Courage

For over a decade, my colleague and wife, Jacque Thousand, and I have been asking hundreds of thousands of people to identify the goals or outcomes of education that are important to them. We have been impressed with the similarity of responses from respondents in the United States, Canada, Latin America, Asia, Europe, Australia, New Zealand, the Middle East, and Micronesia. Wherever we ask the question, people identify the same kinds of desired goals or outcomes. Their responses can be represented by the "Circle of Courage" visual borrowed from



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1999 KEYNOTE ADDRESS

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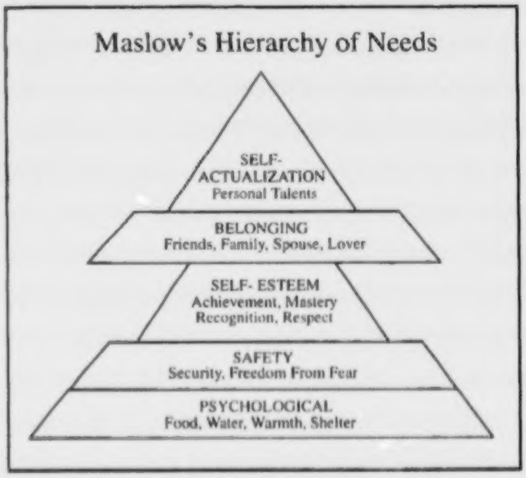
the Native American culture, the Lakota in particular. The Lakota wanted to create courageous youth by instilling within them four characteristics — belonging, mastery, independence and generosity.

I believe everything that you identified as goals of education will fall into one of those four categories. When you identify outcomes such as the ability to get along with others, to form relationships, feel good about yourself and be part of a community, you are speaking of belonging. When you identify outcomes such as reaching one's potential, developing mastery and competence, being a well-rounded individual, you are speaking of mastery. When you identify outcomes such as the ability to be a lifelong learner, to be flexible, to be a risk taker, and to have a choice in where you live, work, recreate, and with whom you associate, you speak of independence. When you identify outcomes such as being a caring member of society, socially responsible, giving something back to one's community, valuing of diversity, empathy and caring, you are speaking of generosity. The Lakota purposely represent all four of these concepts in a circle, a medicine wheel, to remind us that if one or more of these components are missing, the circle will collapse and we will not achieve the future that we want for our children.

We must assure that all of these outcomes are equally emphasized and valued within our educational system. Society, due to political convenience and economic consideration, oftentimes emphasizes mastery and independence at the cost and expense of belonging and generosity. There is, however, a danger to any society that over-emphasizes academics at the cost or expense of social and life skills. That danger is clearly articulated in a letter written to teachers by Haim Ginott: *"Dear teacher, I am the survivor of a concentration camp. My eyes have seen what no man should witness — gas chambers built by learned engineers, children poisoned by educated physicians, infants killed by trained nurses, women and babies shot and burned by high school and college graduates. So I am suspicious of education. My request is to help your students become human. Your efforts must never produce learned monsters, skilled psychopaths, educated Eichmanns. Reading, writing, and arithmetic are important only if they serve to make our children more humane."*



(The Inversion of Maslow's Hierarchy; N. Kunc)

If the Circle of Courage goals are, indeed, the desired goals of education, then every single thing we do in education should be evaluated in terms of whether or not it leads to the desired outcomes of belonging, mastery, independence, and generosity. The curriculum, instruction, assessment, discipline, staffing patterns, and the places where we choose to educate our children should be assessed in terms of their ability to facilitate Circle of Courage outcomes.

Belonging is an essential component of every theory of motivation of which I am aware. Norman Kunc has encouraged many of us to revisit Maslow's Hierarchy of Needs. Maslow taught us that once you belong, you develop a positive self-esteem. Then you begin to achieve and then — and only then — can you become a self-actualized human being. Norman reminds us that historical exclusionary responses to diversity oftentimes have denied children, youth, and adults of belonging because we have inverted Maslow's Hierarchy of Needs. Every time you say to a person, "You need to go some place else because you look different, walk different, talk different, act different, or learn different," you are saying to them, "You cannot belong until you achieve," thus inverting Maslow's Hierarchy. This inversion of Maslow's Hierarchy creates a powerful Catch 22 because we cannot achieve until we belong.

◆

"We are now at a point where we must educate our children in what no one knew yesterday and prepare our schools for what no one knows yet."

◆

We also have ample evidence that many special and general education practices have robbed students of mastery. Let us reflect for a moment on the basic premise of special education that resulted in the development of a continuum of placements. The premise was "students with [disabilities] were going to benefit from a unique body of knowledge, from smaller classes staffed by specially trained teachers who used specialized materials." That was what we believed when the federal legislation guaranteeing students with disabilities the right to a free appropriate education in the least restrictive environment was enacted in 1975. But in a review of the efficacy studies, conducted from the mid-to-late 80's, Lipsky and Gartner concluded, *"There is no compelling body of evidence demonstrating that segregated special education programs have significant benefit for students."*

In the mid-90's, Baker, Wang, and Walberg conducted three meta-analyses

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across every disability category, to compare the achievement of children with disabilities educated with typical children to the achievement of students with disabilities who were educated in resource rooms, special classes, and special schools. The research revealed that "special needs students educated in general education environments did better both academically and socially than comparable students in non-inclusive settings."

Frequently, people identify productivity and employment as an indicator of independence. A national longitudinal study revealed that more than 40% of the graduates of special education are unemployed one year after high school. In contrast, studies have shown that students who are included have a higher rate of post-secondary employment than those who are educated in more restrictive environments do.

When I started to think about productivity from a futuristic perspective, it became clear to me that being a productive member of society would extend beyond one's work. What kind of work is going to exist in the future? Consider that 80% of the employees of McDonalds will be replaced by robotics. The labor-intensive work of the garment industry has moved to developing nations because of cheaper labor and machines are predicted to replace those workers, as well. We live in a world of over six billion people, many of whom will have less or no work. Maybe in the future, we will have the foresight to view generosity, community service, giving something back to one's community, and caring for children and the elderly as strong indicators of productivity.

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Many of our schools assess success based solely upon oral and written efficiency and literacy in English, ignoring our history as a multilingual nation and a global economy.

◆

As Grant Wiggins reminds us, "We will not successfully restructure schools to be effective until we stop seeing diversity in our students as a problem."

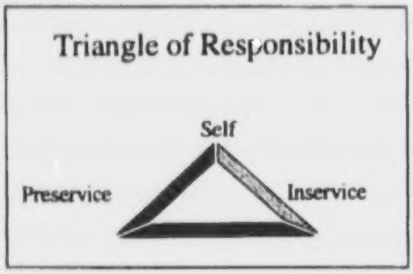
◆

I must admit that I am troubled when I visit some so-called "inclusive schools." I am troubled by the lack of opportunity for many children who do not have English as a primary language, children who are identified as disabled, and children who are considered at-risk to give back to be generous, contributing members of their community. As Dr. King reminds us, *"Anybody can be great because anybody can serve. You don't have to make your subject and verb agree to serve. You don't need a college degree to serve. You only need a heart filled with grace and a soul generated by love."* I would add that you also need the opportunity to be generous. We must recognize the gifts in every child, assist them in developing their competence, and give them opportunities to be generous.

The Intractability of Schools

Five hundred years ago, Comenius said, *"In spite of all of our efforts, they remain basically the same."* He was speaking of the school reform efforts of his day. Seymour Sarason, speaking of the school reform efforts of our day noted that, *"Systems change is not for the conceptually or interpersonally fainthearted."* If we want to create positive futures for our children, we must demonstrate the conceptual, technical, and interpersonal skills necessary to confront the five reasons why schools have been so intractable.

The first reason for the intractability of schools is inadequate teacher preparation. The solution to inadequate teacher preparation lies within a triangle of responsibility comprised of preservice, inservice, and personal dimensions. We have to examine our preservice education in light of the fact that a large number of teachers who will soon be entering our profession and our nation's classrooms are increasingly more diverse. Are we adequately preparing new teachers to successfully inherit diverse classrooms and to meaningfully relate to and motivate all of their students?



Triangle of Responsibility

We also have to deal with inservice issues. I don't wish to be depressing, but the half-life of an educator's work life is now estimated to be five years. We know in the year 2000 only half of what we will need to know in 2005 to do our jobs. This requires intensive, on-going quality staff development for personnel working in our nation's schools to keep pace with change. Finally, those of us working in education must assume personal responsibility for becoming what we want our students to be — life-long learners. Our working conditions in education have changed. If we are going to call ourselves professionals, than we must continually acquire the skills to do the jobs we are paid to do.

The second reason for the intractability of schools is inappropriate organizational structures, policies, practices and procedures. Organizational structures must be examined to determine whether or not they facilitate or erect barriers to the attainment of the Circle of Courage

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Inappropriate Organizational Structures, Policies, Practices, & Procedures

- **Teachers tell, students repeat**
- **Teachers run the class**
- **Verbal/Linguistic & Mathematical/Logical Intelligences are valued**
- **Success is dependent upon oral and written proficiency and literacy in English**
- **Students are prepared for the assembly line of an agrarian society**

outcomes. Think about the basic overall structure of schooling today compared to when you went to school. How much have schools changed? In how many places do the same organizational characteristics that existed when we were students still exist?

Many of our schools still are preparing our students to go out and inherit an agrarian society or attain jobs on an assembly line rather than preparing them to live in a globally complex, interdependent world. Many of our schools assess success based solely upon oral and written efficiency and literacy in English, ignoring our history as a multilingual nation and a global economy. All the way back to 1664, when New Amsterdam, Manhattan Island passed from the Dutch to the English, 18 different languages were spoken.

A decade ago Benjamin reminded us, *"The future will arrive ahead of schedule."* What's going to help us get to the future we desire? The reauthorization of the Individuals with Disabilities Education Act (IDEA) for the first time requires that children with disabilities must have access to the general curriculum. We must utilize the principle of universal design to guarantee universal access to three dimensions of curriculum — content, process, and product. All students must have access to the content and we must assure that that content emphasizes belonging, mastery, independence and generosity. There must be universal access to the processes of learning — helping students make sense out of what it is that they are learning. And, there must be universal access to the products of education — how students demonstrate what they have learned and how we meaningfully and authentically assess their progress.

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We need to ask ourselves, "Where is the disability? Is it in the student or is it in the system that we have created and maintained?"

◆

There are many promising practices from general education, special education, and multicultural and bilingual education that can facilitate universal access to the general curriculum. We must hold ourselves accountable for quality implementation of these practices so that, as Ian Pumpian says, *"we have good examples of good practices rather than bad examples of a good practice."*

Promising Practices

- **Multiple Intelligences Theory**
- **Authentic &Alternate Assessment**
- **Constructivist Approach**
- **Multi-level Instruction**
- **Curriculum Overlapping**
- **Differentiated Instruction**
- **Literature Circles**
- **Bilingual Education**
- **Facilitated Communication**
- **ESL**
- **Multicultural Education**
- **Multi-age Grouping**
- **Looping**
- **Block Scheduling**
- **Team Teaching**
- **Collaborative Planning**
- **Peer Tutors**
- **Peer Buddies**
- **Cooperative Group Learning**
- **Tiered Assignments**
- **Technology**
- **Positive Supports**

A third reason often cited for the intractability of schools is inadequate attention to the culture of schooling. Michael Fullan, a guru of systems change, reminds us that true school reform is not about this innovation or that innovation but rather a culture change. Changing the culture of schools is essential because as David Rothsteder notes, the prevalent culture of schooling is *"consumed with who doesn't belong, rather than making sure everyone does belong."* Further, as Grant Wiggins reminds us, *"We will not successfully restructure schools to be effective until we stop seeing diversity in our students as a problem."*

To create the culture we desire, we need to operate out of assumptions and beliefs that will facilitate the attainment of the Circle of Courage outcomes. What kinds of assumptions and beliefs will lead us to the attainment of the Circle of Courage outcomes? In accordance with Anne Donnellan's "Criteria of the Least Dangerous Assumption," we must assure that every child is viewed as competent and our foremost responsibilities are to cause no harm to that child and instead, help that child fulfill his or her need to belong. We must assume all behaviors are an attempt to communicate and become more skilled at understanding the communicative intent of behavior and in the facilitation of communication. We must believe in families and work with and for them rather than blaming them for their troubles. Finally, we must believe creativity and collaborative teaming are essential to the formulation of personalized responses to the needs of children. According to Pierre Tielhard de Chardin, *"Our duty is to proceed as if limits to our ability do not exist [because] we are collaborators in creation."*

What kind of a culture would exist in schools if we had a Student Bill of Rights guaranteeing that every student would have access to a) effective instruction, b) personalized accommodations, and c) a motivating school climate? Many people are concerned with student rule violating behavior.

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What percentage of rule violating behavior would disappear if these student rights were guaranteed?

There is a strong connection between culture and curriculum. We must examine our curriculum to be sure that the concept and practice of "care" (a desired cultural foundation) is visible. Nel Noddings instructs us that, *"all children must learn to care for other human beings and all must find an ultimate concern in some center of care; care for self, intimate others, associates, acquaintances, distant others, for animals, for plants, the physical environment, objects, instruments, for ideas."*

Some people may view words such as care and belonging as "soft" words, incompatible with "hard" words such as curriculum. I'd ask those critics to review the quote I just read from Nel Noddings and challenge them to identify an area of curriculum that isn't represented through care. We can simultaneously teach children to care while they learn other important curricular principles, concepts, and facts. Think how much more meaningful and relevant our student's learning would be if they understood the connection between what they were learning and the concept of care.

We also must examine our curriculum in terms of social justice and its function as a catalyst for positive change. Freire reminds us that *"Any curriculum that ignores racism, sexism, the exploitation of the workers and other forms of oppression inhibits the expansion of consciousness, blocks our creativity, decreases social action for change and supports the status quo of oppression."* The creation and maintenance of school cultures which welcome, value, and support the diverse academic and social learning of all students in shared environments and experiences for the purpose of attaining the goals of education necessitates changing the status quo.

Our effort to change the culture of schooling will be enhanced if we in the inclusive school movement joined forces with other progressive movements such as Critical Pedagogy and Democratic Schooling. We have much to learn from re-visiting the teaching of pioneers in progressive school and social movements such as Maria Montessori, Paolo Freire, and John Dewey.

For example, Apple and Bean describe the implications of Dewey's notions of democratic schooling by noting that *"those involved in democratic schooling see themselves as participants in a community of learning. By their very nature these communities are diverse and that diversity is prized, not viewed as a problem. Such communities include people who reflect differences in age, culture, ethnicity, gender, socio-economic class, aspiration, and abilities. These differences enrich the community and the range of views it might consider. Separating people of any age on the basis of these differences or using labels to stereotype them simply creates divisions and status systems that detract from the democratic nature of the community and the dignity of the individual against whom such practices work so harshly. While the community prizes diversity it also has a sense of shared purpose. The common good is an essential feature of democracy and for this reason the community of learners in a democratic school is marked by an emphasis on cooperation and collaboration rather than competition."*

I'd like to make one final point about culture. If we are serious about creating a culture that will lead our children and youth to the attainment of the Circle of Courage outcomes, we also must commit to creating a school culture that will lead the adults to these outcomes, as well. We need to answer some important questions. In what ways can we create a greater sense of belonging among the people who work and learn in our schools? In what ways can we help the adult as well as the student members of the school community to achieve greater mastery and confidence? In what ways can we encourage the student and adult members of the school community to be independent, critical thinkers, problem solvers, risk takers and generous, contributing, collaborating members of their school community?

The fourth reason for the intractability of schools is that we have been busy perfecting a model that has allowed us to discard all evidence that what we're doing isn't working. In essence we say to students, "You do not learn the way that I teach, so go away." Let's take a moment to examine the current situation:

1. 2% of our nation's students are being home schooled;
2. 25% of our nation's children are enrolled in some form of alternative school (e.g. charter schools, magnet schools); and
3. 50% of our nation's children are not full-time placed in general education classrooms. They are part- to full-time placed in special, bilingual, multi-cultural, gifted, vocational, and at-risk educational programs.

We need to ask ourselves, "Where is the disability? Is it in the student or is it in the system that we have created and maintained?" Disability is a social construct that changes from one to the next culture and across time. World Health Organization data reveals that the proportion of children within a society identified as disabled increases in proportion to that society's level of "development." Wouldn't you think that a more developed society would be better equipped to embrace diversity and view people as "differently-abled" rather than disabled?

We must be cognizant of the fact that reform initiatives create disability. For example, when the Soviets launched the Sputnik satellite, the United States responded with major school reform initiatives, emphasizing math and science education. One of the consequences of this action was a large increase in the number of students identified as having a learning disability. In the mid-80's, in response to economic competition from Japan, reports such as A Nation at Risk sparked major reform initiatives in our nation's schools. The result this time was not only an increase in the number of people labeled disabled, but also an increase in the number of categories or types of disability.

Today, the focus of school reform is on standards. Is there anyone sitting in this audience who doubts that this, too, will lead to an increase in the number of students perceived as disabled? We can

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An official Lane Education Service District application form must be submitted in order to be considered for this position.

Keynote Remarks: Kyle Glozier

Good morning, TASH. My name is Kyle Glozier. I go to West Green Middle School in New Freeport, Pennsylvania. I am in the eighth grade and I have been included in regular education since kindergarten. Parents don't want to put their kids with disabilities in regular schools because they listen to the experts who say they will not learn in regular schools. That is totally false.

School is important because you need to learn and we learn just as much from our classmates as we do from our teachers. Schools need to stop babysitting and put kids with disabilities in classrooms with kids that do not have disabilities. This will help to enforce the IDEA. Doing this will help kids receive the knowledge they need to survive. They will learn how to get along and interact with kids that don't have disabilities. Kids without disabilities will learn that people with disabilities are okay and there is no reason to be afraid of them.

Including kids with disabilities from the very beginning will begin to change society as a whole. Together we can teach society to not push people with disabilities out of the way, forgetting that we deserve our rights as citizens of the United States. When I go home and see kids that are in segregated classrooms, I wonder why these kids aren't in regular education like I am. More moms and dads like mine need to get involved with disability rights so they can see other people in wheelchairs and have role models and heroes like Justin Dart. After high school, you have to move out of your parents' houses and go to college or tech school. If you stay with your family, they will die eventually and what will happen to you? More than likely you will end up in a nursing home.

I hope one day to study journalism or even go to law school. Who knows? I may be the first person with cerebral palsy to become the president of the United States. I believe that anyone can do anything they want to do. Disability pride is not having to feel sorry for yourself. It's liking yourself for who you are. Discrimination is when people don't allow people of other races, religions, sexual orientations or abilities to go to all the places they want to go. When people with disabilities can't get on the bus, they get angry that they can't go everywhere they want to go just like Rosa Parks.

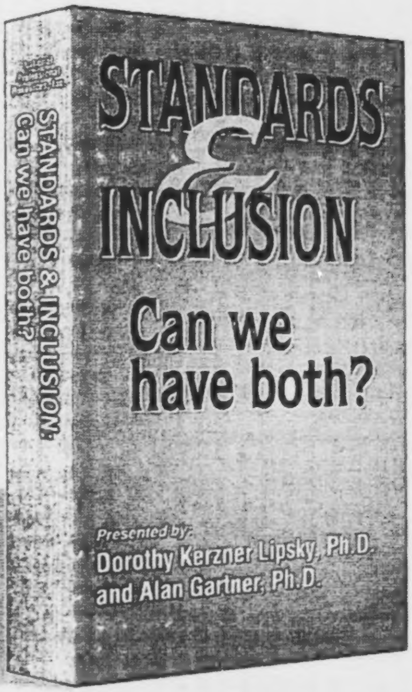
Society is changing slowly, but we need even more change to keep on pushing into the new millennium. We need to keep on pushing until all people are free from institutions and fully included into society. That reminds me of the song that a good friend of mine sings, "Tear Down the Walls."

One verse says,
"Can't you see the justice coming at you now?
It's coming down the road.
It's coming down the street.
It's coming for your kids.
They're going to hate you if you don't act now."

When I ask my brother, Nigel, "how do you feel having me as your brother?" he answers, "Good. I like you. You're nice." And when I asked my brother, Jason, the same question, he says "you're okay, but you're really scary when you're mad."

When I asked an adult friend who uses a wheelchair how do your kids feel having you as a mom, she said they treat her like anyone else, and treat her brother with a cognizant disability just like everyone else, too. If all people are exposed to people with disabilities at an early age, the disability makes no difference at all. They see just another person. They see past the disability. This is how we need to see society change. It is our turn now. Thank you.

Standards & Inclusion: Can we have both?



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Dorothy
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Alan
Gartner

About the Authors:
Dorothy Kerzner Lipsky is Director of the National Center on Educational Restructuring and Inclusion, and Alan Gartner is Dean for Research. Both are at The Graduate School and University Center, The City University of New York.

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FUNDING FREEDOM CITIZENSHIP

The First International Conference on

Self-Determination & Individualized Funding

General Overview

Over 1,200 people from around the world are expected to participate in this groundbreaking conference, including people with disabilities, family members, community advocates, professionals, service providers, researchers, administrators, and government officials. The conference will be rich in opportunity and out-comes, with topics and speakers being broad enough to encourage participation from other isability areas including developmental disability, the independent living movement, seniors, and people involved in the mental health movement. During the past decade individualized funding (also known as direct payments or individualized budgets) and self-determination have become focal points for the worldwide disability movement. Individualized funding is now recognized as a fundamental require-ment for self-determination, enabling people to purchase, and therefore gain control over, the supports needed to enjoy meaningful lives in the community.

Desired Outcome:

1. The conference will yield an international "Declaration" through the use of three small groups called Prospectors Groups. The groups have been so chosen, because, like people sieving a stream for grains of gold, they will be searching for the special grains of truthfrom the information shared at the conference that need to go into the Declaration.The Declaration may include such items as:

- The key principles and aims of individualized funding
- Methods of putting individualized funding into action, which support those principles and aims
- Actions that stakeholder groups (e.g. people with disabilities, governments; service providers) should take to support individualized funding

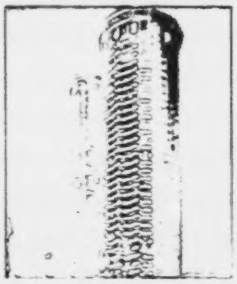
2. A written report of conference proceedings will be produced by Steve Dowson and Brian Salisbury, Co-chairs of the program planning committee. All attendees will receive this report approximately 2–3 months post conference.

GUIDING PRINCIPLES

The conference planning committee is using the following three principles when planning the events and structure of the conference:

∗ Inclusive and Accessible
∗ International
∗ Searching for Consensus

For a copy of conference brochure or more information about the conference, please contact Denise Marshall at dmarsh@tash.org or 1-800-482-8274 x 103 or visit the website at http://members.home.net/directfunding/



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July 29-31, 2000

Preliminary Conference Agenda

Saturday, July 29, 2000

1 p.m. – 9:00 p.m.	Conference Registration Begins
2 p.m. - 5:00 p.m.	Pre Conference Sessions
6:00 p.m. – 9:00 p.m.	Opening Reception

Sunday, July 30, 2000

7:30 a.m. - 9:00 a.m.	Conference Registration
8:45 a.m. - 10:15 a.m.	OPENING PLENARY
11:oo a.m. - 12:30 p.m.	Concurrent Sessions
12:30 p.m. 2:00 p.m.	Lunch
1:45 p.m. - 3:15 p.m.	Concurrent Sessions
3:45 p.m. - 5:15 p.m.	Concurrent Sessions

Monday, July 31, 2000

8:45 a.m. - 10:15 a.m.	Concurrent Sessions
10:45 a.m. - 12:15 p.m.	Concurrent Sessions
12:45 p.m. - 3:00 p.m.	Lunch and Closing Plenary Presentation of conference declaration and closing keynote remarks

Many groups from around the world have signed on to sponsor or support this exciting conference. Sponsor's contributions will be devoted entirely to assist self-advocates, parents, and international participants to participate in the conference. If you are interested in supporting or sponsoring the conference, please contact Nancy Weiss at 1-800-482-8274 or nweiss@tash.org

Founding Organizations: *TASH - Disability Advocacy Worldwide, Self-Advocates Becoming Empowered, British Columbia Coalition for People with Disabilities, National Program Office on Self-Determination; A program of the Robert Wood Johnson Foundation, Administration on Developmental Disabilities, Canadian Association for Community Living, The Arc of the United States, American Association on Mental Retardation, The Inter-American Institute on Disability, The World Institute on Disability, and Inclusion Internationale*

Sponsoring Organizations: *Glendale Foundation for Research and Community Support, Center on Human Policy, British Columbia Association for Community Living, British Columbia Paraplegic Association, and the Presidential Task Force on Employment of Adults with Disabilities*

Supporting Organizations: *People First of Washington, The Arc of Washington State, Washington Initiative on Supported Employment, CARF, Langley Association for Community Living, Community Living Society, VELA Microboard Association, MSA Society for Community Living, Greater Vancouver Community Services Society, Speaking for Ourselves, Planned Life Advocacy Network, Values Into Action, Central England People First, and the Community Living Journal*

Inclusion & Universal Cooperation

BY ROSANGELA BERMAN BIELER

In nature, all living creatures have the same structure of genetic code – the DNA. At a certain point of the process the codes start to differentiate, bringing specific identity to each species, each creature. One of the beauties of life is that this same DNA that generates so many similarities among living beings is what also makes them so different and individual.

While generating her family, Mother Nature made sure that life would contain, at the very same time, simplicity and complexity. Each piece of the puzzle, even the tiniest part of it, has a role in the way — and the only way — that the puzzle can be assembled and kept in balance. From the perspective of Human Kind, this requires humility and pride to understand and accept that we are really, really small in the whole context of the universe, yet each one of us has a role that must be played to accomplish its balance. We should learn how to live in diversity, how to accept the individual differences and how to make them benefit us all.

It seems that we, disabled people, have that vision. We can feel and understand such concepts. This vision makes us responsible and makes us into good role models, spokespersons for the transformations that society is just starting to go through. Are we ready for it?

In Brazil, we tell a story of a hummingbird that, during a very big fire in the forest, was seen coming back and forth, carrying water in his beak and dropping it over the fire. The other animals, most of them bigger and stronger than the hummingbird, were all running away as fast as they could, thinking only to save their own skins. While running, a lion watching the hummingbird asked him if he had not yet realized that he would not extinguish the fire with such drops of water, but instead, he would get himself killed. Without stopping work, the tired hummingbird then told the lion: "I'm just doing my part."

In our daily lives, when we make decisions, most of the time we have to choose between the lion's and the hummingbird's vision of the world, of life and of ourselves. Do we normally think or truly care about the ones around us?

Ms. Berman Bieler was one of the keynote speakers at the December 1999 TASH Annual Conference in Chicago, Illinois.

Earth's Population

Dr. Phillip M Harter, MD, FACEP from Stanford University, School of Medicine recently stated that "*If we could shrink the earth's population to a village of precisely 100 people, with all the existing human ratios remaining the same, it would look something like the following:*

There would be:

- 57 Asians; 21 Europeans; 14 from the Western Hemisphere, both north and south; 8 Africans
- 52 would be female; 48 would be male
- 70 would be non-white; 30 would be white
- 70 would be non-Christian; 30 would be Christian
- 89 would be heterosexual; 11 would be homosexual
- 6 people would possess 59% of the entire world's wealth and all 6 would be from the US.
- 80 would live in substandard housing
- 70 would be unable to read
- 50 would suffer from malnutrition
- 1 would be near death; 1 would be near birth
- 1 would have a college education
- 1 would own a computer

And he concludes: "*When one considers our world from such a compressed perspective, the need for acceptance, understanding and education becomes glaringly apparent.*"

The fact that disability is not reflected in these statistics does not surprise us. Even while being a relevant proportion of each one of these categories, we are still out of the self-image of society. Society does not count us in, as peers, even when trying to portray all its diversity.

Poverty & Disability

Poverty is a deprivation of the essential assets and opportunities to which every human is entitled. Everyone should have access to basic education and primary health services. Beyond income and basic services, individuals and societies are also poor - and then tend to remain so - if they are not empowered to participate in making the decisions that shape their lives.

Approximately four-fifths of the world's disabled people live in developing countries. Poverty creates conditions for disability and disability reinforces poverty. Exclusion and marginalization of disabled people reduce their opportunities to contribute productively to the household and the community, and thus increase poverty.

Disability is expected to increase in the future, if economic growth remains unbalanced and does not accommodate equity, environment and social concerns. Disability will also increase as society becomes older. The proportion of disabled children in developing countries is also higher compared to developed countries. Many types of disabilities that are no longer or rarely being experienced in healthy countries such as polio, landmine injuries, and leprosy are still common in poor countries.

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Disability colors and sharpens all aspects and conditions of human kind. It accentuates and aggravates situations of discrimination, prejudice and exclusion faced by women, by minorities, by poor and all other underprivileged groups. It also clearly highlights and illustrates the diverse physical, mental, and sensorial aspects of being human, obliging society to react, interact and reflect about it.

Inclusion and Full Participation

The process of reaching empowerment and full participation as citizens is long and ongoing. It obliges us to forge our history, personal and collective, on a daily basis. In fact, full participation can only be truly achieved in an inclusive society, where each and all of us is considered to be an integral part of the whole, of the community, which in turn is a responsibility of all its members. But to achieve this "ideal society," constant vigil is required.

Our existence and our lives, our constant fight for acceptance and recognition are a testimony of resistance against exclusion. We are still here, after millennia of discrimination, marginalization and even in some cases elimination of disabled people from the face of the earth through racist and eugenic initiatives. But, the human being resists and survives because it is a form of life meant to do so.

Because we, people with disabilities, have historically and still face discrimination and exclusion in our daily life, we are no doubt the group of human beings that has discussed and analyzed in greatest depth the concept of diversity and inclusion.

It is our role, our turn to offer our testimony, our knowledge, our wisdom to society at this very same moment when, although not yet recognized by many, it's time to move ahead. We already have the feeling, the concept, the understanding, the words to explain what an inclusive society means. Now it's time to incorporate these concepts into our own lives, attitudes and actions. Only in this way can we truly help to open minds and hearts toward a society for all. We have this huge responsibility and we don't have the right to fail.

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Now we have a new challenge: instead of proving we are 10% (of the world's population), we must convince society we are an irreplaceable part of the 100%. It may seem pure rhetoric, but it is a very crucial switch in the disability movement's approach. Now that we are beginning to achieve recognition as a group within the many excluded groups that are navigating around society, it's time to mix ourselves again with everybody else.

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Part of the Whole

For the last 20 years or more, it has been claimed we represent 10% of the world's population, with specific rights that would give us equal opportunity to survive and join our communities. We continue requesting that society accept us and recognize our rights. We are still outsiders knocking on the door for shelter.

Now we have a new challenge: instead of proving we are 10% (of the world's population), we must convince society we are an irreplaceable part of the 100%. It may seem pure rhetoric, but it is a very crucial switch in the disability movement's approach. Now that we are beginning to achieve recognition as a group within the many excluded groups that are navigating around society, it's time to mix ourselves again, with everybody else, and get in. We want to be identified within the regular 100%, mixed with the other children, the other elders, the ones who are too tall or too fat, the blacks, the Indians, the foreign, the poor, the different - all these different parts of the same body, the same society.

We should not fear that this means we will lose our identity or the advances that we've already achieved. This will mean expansion of possibilities, establishment of new partnerships, mutual support and solidarity – universal cooperation.

For 15-20 years we testified among strong social minority groups defining themselves as excluded. On another "stream" we have seen ecology groups bringing to discussion the concept of diversity. But, following Human Nature each one of these groups was not really getting the whole picture, but only their specific interests. It was once said that the history of the world is the history of exclusion. This is an approach that is not acceptable anymore.

We, the whole society, have to start seeing each other as one, with many faces and ways of expression. We have to start practicing what we request others to do. We have to think inclusively and to live inclusively.

Time for Cooperation

We, as people with disabilities, tend to only represent and protect our own agendas. But we want everybody else to include us on their agendas, as a priority. We have the right. Society is in debt to us. But who is "society"? In our own lives, don't we also exclude, discriminate, hate?

Adults with disabilities have rarely advocated for the rights of children with disabilities. This mission was led almost exclusively by parents, as their cause was different from ours. Still in many countries, psychiatric survivors are not accepted as part of the disability community. In 1999 we are still creating international forums to gather some disability organizations, with the hidden purpose of excluding others from participation. We still see the different areas of disability fighting against each other, professionals and families being treated as enemies by organizations of people with disabilities and vice-versa. Of course there are historic reasons for all of these attitudes but we cannot use this as an excuse anymore.

In other spheres, we see women's movements excluding the disabled

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women's cause from their fights. We see total lack of solidarity and collaboration within the social movement, as if we could solve the problems of one group without solving the problems of society as a whole.

We see the United Nations excluding people who speak languages other than English from participation in the discussions. Far too many of the U.N. and its agencies' documents are still only available in English, when not translated through an isolated initiative by an organization in a member country. Even now, in the globalization era, communication and information are meant to be luxuries of just a few.

With the era of globalization, information circulates instantly. The notion of time and space is modified and today we participate in a faster world, more global, more technological, more interactive… but not still inclusive.

International programs to assist economic and social development should require minimum accessibility standards in all infrastructure projects, including technology and communications, to ensure that all people are fully included in the life of their communities.

We have the luxury of living in the U.S., this wonderful country, probably the one that gives the most for its inhabitants. My country, Brazil, unfortunately suffers from one of the worst distributions of welfare in the world. But if we put it in perspective, the U.S. has one twentieth of the world population and accumulates one-third of all the welfare of the world. Universal cooperation is urgently needed.

A Future for All

Today, the issue of inclusion permeates our political speech, not just in the area of disability. And this has to be coherent with our practice, both internally within the movement as well as in relationships with the public in general.

As Justin Dart, a powerful leader and humanist of the disability movement in the U.S. says:

"We must change a value system that defines winning as gaining symbols of prestige that make one person feel superior to other people. Winning is when you fulfill your personal potential to create a life of quality and dignity for yourself and for all." And he concludes: "Life is not a toy store game that requires losers. Let us declare the 21st Century as the Century of victory for all."

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Our generation of the disability community has had the privilege of helping to generate new paradigms for the future, within the universe of diversity. Now we have the chance and the challenge to contribute to their actual implementation.

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Prejudice and discrimination are the basis of exclusion. The concept of inclusion is holistic and it can only successfully exist if absorbed and worked out by the whole society, together.

Notice the major shifts of approach, for instance, within the area of disability over the last century: Among the "old paradigms" was initially institutionalization, where all who were "different" were segregated, treated in isolation of the social context. Later came patterns of "normalization" and "integration" through which society intended "to adapt" those considered "different" to the existent status quo; a society that excludes everything that does not quit fit within its frame.

Human beings have not been intrinsically inclusive but, on the contrary, discriminatory by nature, fearing and rejecting everything that is different, everything that it does not know or understand. We built a society planned and projected for a man's pattern close to "normality" that, according to international statistics, doesn't correspond to the real condition of over 80% of the population.

Now we are talking about reconstruction; a new concept of society, inclusive, to be planned for all. It means we will no longer plan our physical spaces and our services just for the mythical average man anymore, but for the real population, including older people, children, pregnant women, obese, people temporarily impaired, wheelchair users, blind or visually impaired, deaf or hearing impaired and so on.

We are talking about diversity: a new society, from and for men and women of all the ages and physical conditions, of all origins, races, cultures, religions, sexual and ideological options, social conditions. The only kind of society that can be sustainable and allow true and full human development.

This future requires the growth of human and personal development, tolerance, acceptance, solidarity and cooperation.

Our generation of the disability community has had the privilege of helping to generate new paradigms for the future, within the universe of diversity. Now we have the chance and the challenge to contribute to their actual implementation. We will only be able to do this if, serving as individuals and institutions, we apply these new paradigms of this still utopian inclusive society as the basis for our daily decisions and personal and professional actions.

Values such as tolerance, solidarity and cooperation should lose their almost religious stigma and become part of our daily lives — concepts to be truly practiced, with mind and heart.

Here, now, day-by-day, we have the responsibility of helping to build toward the magic moment of transformation — when we will sit down to the same table, councils representing human groups of every kind; a "Council of Jedi " celebrating the force, wisdom and fortune of diversity.

Rosangela Berman Bieler is President of the Inter-American Institute on Disability, headquartered in Rockville, Maryland. Ms. Berman Bieler may be contacted at 301-838-3031 (phone); 301-838-3029 (fax); or IIDisab@aol.com *(e-mail).*

The TASH Elections Committee is seeking Nominations for the TASH Executive Board. Nominations and self-nominations are welcome.

Send a letter describing the nominee, his/her past achievements and his/her commitment to TASH. Please provide the name, address and other contact information (phone, fax, and e-mail) for both the person being nominated and the person making the nomination. All nominations received by May 15, 2000 will be considered by the Elections Committee in their selection of a slate.

PLEASE SEND THE INFORMATION REQUESTED TO:
Elections Committee, c/o Nancy Weiss, TASH,
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Letters can also be faxed to Nancy Weiss at 410-828-6706 or sent by e-mail to nweiss@tash.org

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In Memoriam

James David Sexton 1948 - 1999

The Council for Exceptional Children's (CEC's), Division of Early Childhood (DEC) and the entire early childhood community lost a significant member in the sudden death of J. David Sexton, president of DEC for 1999-2000. David's exceptional leadership and vision for the Division of Early Childhood will be greatly missed. However, he leaves a wonderful legacy of contributions to the Division of Early Childhood and of the Council for Exceptional Children, and his students, university, and community.

Over the course of his distinguished academic career, David taught thousands of students enrolled in early childhood special education and early childhood education programs. His scholarly and profound interpersonal influences will live on in those who were fortunate to learn from and with David.

David's prolific scholarship record attests to his lifelong commitment to the field of early childhood education. He was adamant in his belief that research findings should be combined with cumulative knowledge gained through experience to inform practices in the field.

David was committed to ensuring that CEC's Division of Early Childhood be a force that makes a difference in the overall quality of life for young children with special needs, their families, and the personnel who serve them.

We may take comfort in knowing that in this time of tremendous loss, part of David's legacy will live on through this important work. His enormous strength of character, keen intellect, personal and professional integrity, and sense of human will be remembered often by those who were fortunate to learn and grow from each and every interaction with David.

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Due to overwhelming demand, TASH has reprinted a limited quantity of the JASH Special Issue on Interventions for Young Children with Autism!

Individual and multiple copies are available for purchase for a limited time only!

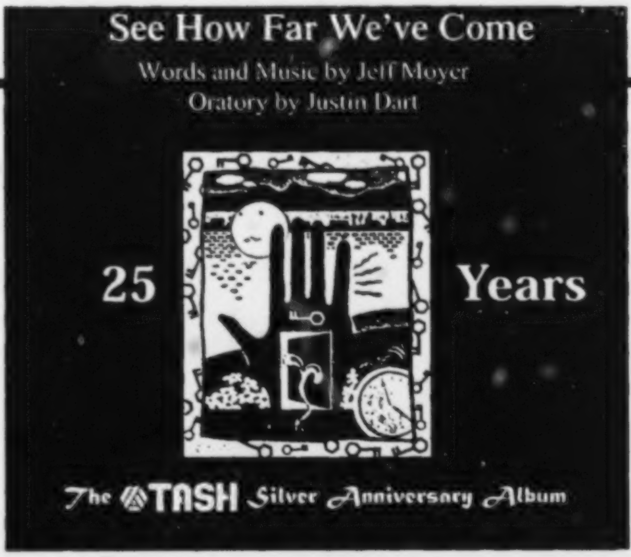
The Fall 1999 JASH, co-edited by Fredda Brown and Linda Bambara, was devoted to Interventions for Young Children with Autism. The purpose of this special issue is to highlight a range of best practices in educational interventions. Several nationally-recognized researchers contributed their latest work in the area of early intervention of children diagnosed with autism. These contributors represent a range of practices -- from behavioral to developmental. Authors include Lynn and Bob Koegel and their colleagues; Stanley Greenspan and Serena Wieder; Steve Anderson and Ray Romancyzk; and Gail McGee and her associates.

These articles are followed by commentary from five leading experts, including Shirley Cohen; Anne Donnellan; Glen Dunlap; Barry Prizant and Emily Rubin; and Richard Simpson. Perspectives from two parents, Claire Choutka and Diana Parisy, are also included.

The mission of this special issue is to bring together a variety of perspectives and models in order to facilitate and generate discussion and synergy in a time characterized by divisiveness and conflict.

To secure additional copies of this special issue of JASH, request an order form from TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204; Phone: 1-800-482-8274; E-mail: jash@tash.org; or visit TASH's web site at http://www.tash.org/publications/jash/special_issue.htm

Don't miss your opportunity to add this special issue of the Journal to your collection!


See How Far We've Come
Words and Music by Jeff Moyer
Oratory by Justin Dart
25
Years
The TASH Silver Anniversary Album

• • •

"For the Crime of Being Different," "Just a Home of My Own," We Are Survivors," "Do You See Me As An Equal?" and the memorable title cut, ***"See How Far We've Come,"*** written in honor of TASH's 25th Anniversary, are just a few of the selections on this incredible CD.

• • •

Don't miss this opportunity to purchase your copy of Jeff Moyer's powerful CD, *"See How Far We've Come."* Selections from this important retrospective on the last quarter century of the U.S. disability rights movement were featured in Jeff's keynote presentation at the 1999 TASH Annual Conference in Chicago.

This moving collection of spoken word and music selections incorporates the stirring and unforgettable oratory of Justin Dart, an internationally prominent leader in the disability rights movement, with the songs and poetry of Jeff Moyer, a leading songwriter, musician, and disability rights activist.

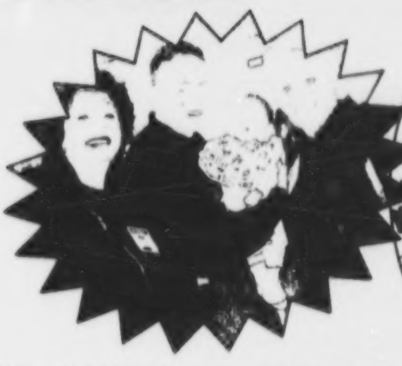
Available on compact disk for $15.00 (add $2.00 shipping for U.S. orders; additional postage will be added to orders outside of the U.S.) For volume discounts, contact Nancy Weiss, 410-828-8274, ext. 101.

Make your check or money order (U.S. dollars) payable to: Jeff Moyer CD, c/o TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, or you may pay using MasterCard, Visa or Discover.

1999 *Conference* HIGHLIGHTS

Larry Gorski, special Assistant to the Mayor and Director of the Chicago Mayor's Office for People with Disabilities, conducted a conference session on voting rights as part of the Governmental Affairs strand.

John Donnelly (left) and Ming-Gon John Lian participate in the Community Living Strand.



Above: (L-r) Nancy Weiss, Executive Director of TASH, Patrick Schwarz, TASH Board Member, Grace Newton (wearing the bib) and Dean Linda Tafel, National-Louis University. National-Louis sponsored the opening night reception.

Left: Even some of the youngest conference participants took a break to pose for a pix (Kiddie Corp. staff from left: Kim (holding Grace), Joyce and Doris; Front row from left: Marsha, Ashley, Kristina, Patrick and Peter)

Right: Keynote presenter Rich Villa (Left) was one of many authors that participated in the Friday evening book signing sponsored by Brookes Publishing.

VALLEY
TASH!
May Peace Prevail On Earth
CHICAGO

Craig Michaels (right) looks on as Larry Gorski accepts the peace pole presented to the Mayor and City of Chicago.

Judith Snow (3rd from the left) celebrated her 50th birthday with a room full of friends and well wishers as part of the Chicago conference. Pictured with Judith are (l-r) Joe Wykowski, P. Sue Kullen (foreground), Jay Klein and Anne Donnellen.

1999 Keynote Speakers

Rich Villa

Diane Coleman

Kyle Glozier

Jeff Moyer

Anne Donnellan

Roseangela Berman-Bieler

and TASH Award Winners

1999 Alice H. Hayden Award

Denise Mautz, winner of the Alice H. Hayden Award for achievements in leadership, teaching, scholarship and service on behalf of people with disabilities.

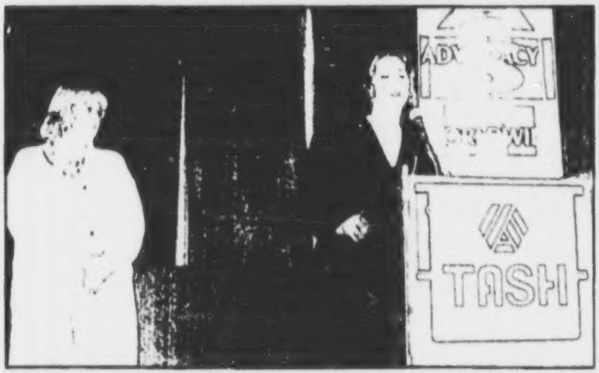
1999 Thomas G. Haring Award for Research

Above: Pam Walker, recipient of the 1999 Thomas G. Haring Award for Research.

1999 Collaboration Award

Elaine Wilson (left) and Lois Curtis and their advocates received the 1999 TASH Collaboration Award for achieving their goals and influencing public policy nationally through the victorious U.S. Supreme Court case, Olmstead v. L.C. and E.W.

1999 Positive Approaches Award


Left: Colleen Thoma (left) and Sara Winter accept the Positive Approaches Award for their important contributions toward public policy in support of positive behavioral approaches in the passage of legislation AB 280, which prohibits the use of aversive procedures in Nevada. Winners not pictured: Barbara Buckley, Eric Beiningen, Ed Guthrie and Stephanie Richter.

1999 Emma Rose Scholarship Award

Susannah Dickman, received the first Emma Rose Scholarship for "advocating for her sons and for championing the cause of inclusion for all."

Thank You

To the following Official Sponsors for their support of the 1999 TASH Annual Conference!

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Hold these dates:
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Look for more information in future issues of the TASH *Newsletter* and on our web site!

THANK YOU TO THE 1999 CONFERENCE VOLUNTEERS

We Couldn't Have Done It Without You!

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TASH

Many thanks to all of the 1999 exhibitors that helped to make the Chicago conference such a success! We greatly appreciate the loyalty of those exhibitors that have been with us over the years, and hope that our newest exhibitors enjoyed the experience.

We look forward to seeing all of you in Miami Beach in December 2000 to help celebrate TASH's 25th anniversary!

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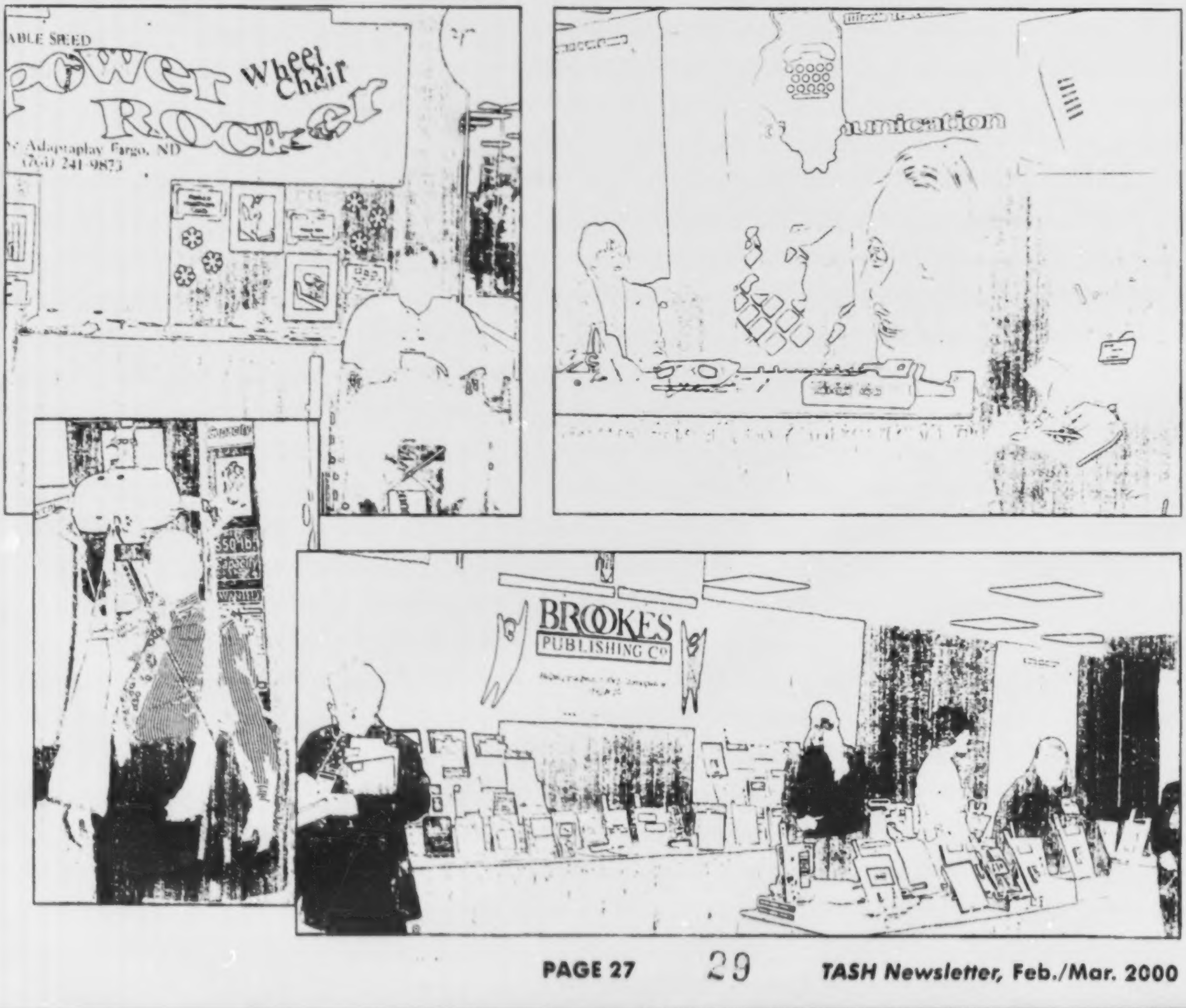

1999 KEYNOTE ADDRESS

Continued from page 12

be big on standards, have high expectations for our students, but we must be short on standardization. One of the defining characteristics of a bureaucracy is a lack of personalization. But the Student Bill of Rights we spoke of earlier calls for personalized accommodations, as does the process for developing individualized educational programs (IEPs) to facilitate the learning of students identified as eligible for special education.

To create the future we want for our children necessitates that we guard against political sloganeering and simple solutions to complex problems. To assume that the solution to the problems facing education in this country will be remedied by simply creating higher standards is like saying the solution to world hunger will be remedied by increasing nutritional standards alone. Slogans such as, "all students will come to school prepared to learn" are naive and miss the point. Students already do come to school prepared to learn. Unfortunately, educators oftentimes are ill-prepared to teach, motivate, and relate to their students.

The fifth and final reason why schools have been so intractable is that many of us who would like to lead others into change are naive and/or cowardly. We are naive because we do not understand the change process. We are naive because we want immediate change despite the fact that true system change requires a minimum of 5 to 7 years. We are cowardly because many of us are unwilling or unprepared to confront the cognitive dissonance, emotional turmoil, and resistance that accompany complex change initiatives.

Demonstrations

- **Between 1996 -2001, China will create 1.8 million inclusive options and train over 1 million teachers in special education**
- **Inclusive education efforts in Burundi, Guyana, Jamaica, Kenya, Mexico, Philippines, South Africa, Bermuda, India, and Viet Nam**
- **92 Nations signed the Salamanca Statement**
- **As of 1993, inclusion models exist in every U.S. State & Canadian Province**
- **Less than 1% of students with disabilities in special schools in Australia, Denmark, Greece, Norway, & Spain**
- **Norway (1975), Iceland (1991), Honduras (1991), Italy (1992), and Austria have mandated inclusion in some or all schools.**

Visions of Change

Della Ambrose developed, and Tim Knoster modified, a model to help us understand and implement complex change. If we want a complex change — such as the creation of schools that are both caring and effective — to occur, we need to combine vision with skills, incentives, resources and an action plan. Put all of these elements together and you will achieve change. If one or more of these components are missing, the result will be confusion, anxiety, resistance, frustration, or the expenditure of a lot of energy without change.

Phil Schlechty reminds us that, "*One of the greatest barriers to school reform has been the lack of a clear and compelling vision.*" We at TASH have a vision. It is clear. It is compelling. It is for all children. And the Circle of Courage represents it. If we want to actualize our vision, we must redouble our efforts to assure that whether a child is included is no longer dependent upon geography — where that child and that child's family happen to live.

To realize our vision for our children requires that we stop being so egocentric, focusing only on what happens in the United States. We need a broader, international view. We have much to learn from other people, cultures, and nations. As I travel to and from different countries working on social justice and education issues, it never ceases to amaze me just how many people in other nations reference international law, policy, and covenants. I never hear that kind of discussion in the United States.

MANAGING COMPLEX CHANGE

VISION	SKILLS	INCENTIVES	RESOURCES	ACTION PLAN	= *CHANGE*
	SKILLS	INCENTIVES	RESOURCES	ACTION PLAN	= *CONFUSION*
VISION		INCENTIVES	RESOURCES	ACTION PLAN	= *ANXIETY*
VISION	SKILLS		RESOURCES	ACTION PLAN	= *RESISTANCE*
VISION	SKILLS	INCENTIVES		ACTION PLAN	= *FRUSTRATION*
VISION	SKILLS	INCENTIVES	RESOURCES		= *TREADMILL*

Adapted from Knoster, T. (1991) Presentation at TASH Conference, Washington D.C. (Adapted by Knoster from Enterprise Group, Ltd.)

We should be referencing and celebrating documents such as the Salamanca Statement, which emerged from the 1994 United Nation's-sponsored World Conference on Special Education. Ninety-two nations signed the Salamanca Statement, which in part reads, "*Education for children with special educational needs should be provided within the regular education system, which has the best potential to combat discriminatory attitudes, create welcoming communities, and build an inclusive society.*" TASH'S vision is shared. There is strength in numbers. We must build regional, national, and international alliances for change.

Klopf observed that, "*...whatever is, is possible.*" Let us pause and celebrate what has been made possible thus far. We have journeyed a long distance from the day Doug Biklen challenged us by saying, "*We have islands of hope. We need to create mainlands of opportunity.*"

And more work remains to be done. We need to gather strength and energy from that which has already been accomplished. As Carlos Castenada reminds us, "*The trick is in what one emphasizes. We either make ourselves miserable or we make ourselves strong. The amount of work is the same.*"

I want to continue the celebration of the results of past efforts before we return to a discussion of the present and the future. We all stand on the shoulders of

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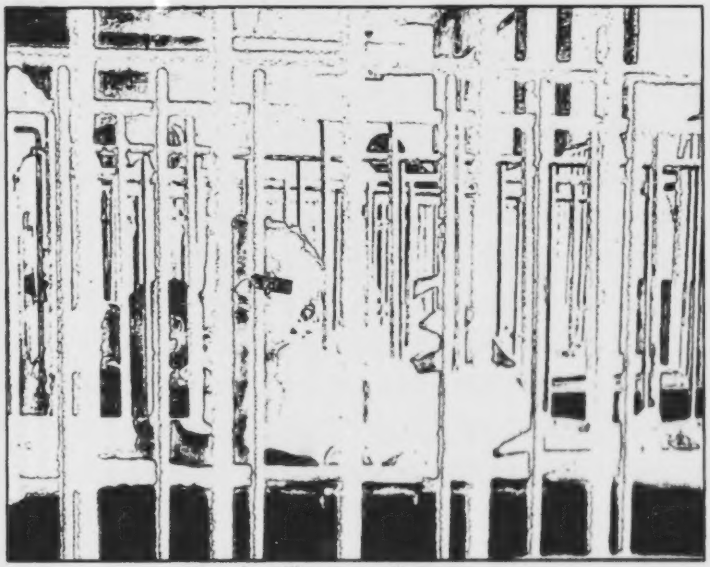
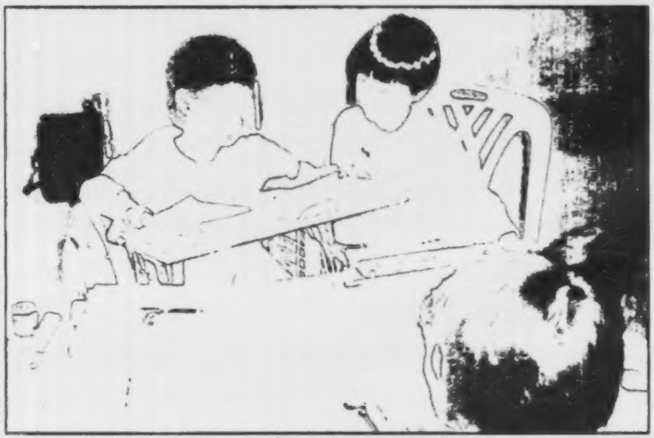
Continued from page 28



Scene from Christmas in Purgatory.



Students working together in a cooperative learning group.

A classroom scene

(Letter from Jody to her teacher)

Bilding me a fewcr

Dear Teachr,
Today Mommy cried. Mommy asked me Jody do oyu realy kn Why You are going to school I said I don't kno why? She said it is caus we are going to be bildiing me a fewchr. I said What is a fewchr wats one look like?

Mommy say everry one need to work realy hard for us kids to make our fewchrs the nicest ones the world can ofer.

Teacher can we start tody to bild me a fewchr? Can you try espeshly hard to make it a nice prity one jest for Mommy and for me?

I Love You teacehr.
Love,
Jody

XXOOXXX

those who have come before us. Look at the institutional picture from Burt Blatt's Christmas in Purgatory to the left.

This picture represents the vision of what people at one time thought was possible and best. That vision changed as a result of the vision, skills, incentives, resource allocation, and actions of the people who preceded us as well as many of the people sitting here today. I would be remiss if I did not point out that, every time our vision of what was possible expanded, it was the parents and self-advocates who had that broader, greater vision long before the professionals. To go from scenes such as those depicted in Christmas in Purgatory to inclusive scenes like these from across the world in 25 to 30 years is indeed cause for celebration.

Let us return to a discussion of the future of education and the struggle we will experience in the present to reach that desired future. I believe that the words of a student, Jody, written to her teacher may help to motivate us to create better futures for all students.

Teacher, parent, policy maker, community member, advocate, fellow student, can we start today to make a better future for our children? Dr. King's words also give us inspiration for the struggle ahead:

"Cowardice asks the question, 'Is it safe?' Expedience asks the question, 'Is it political?' Vanity asks the question, 'Is it popular?' But conscience asks the question, 'Is it right?'"

And there comes a time when one must take the position that it's neither safe, nor politic, nor popular, but it must be made because conscience says that it is right!

The possible future of education is either a terrible or a wonderful thing. The future is dependent upon the actions that we take in the present. These actions are seeds, which bear many vines. The vines may lead to

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1999 KEYNOTE ADDRESS

Continued from page 29

inclusion or exclusion. They can lead to belonging or alienation. They can lead to mastery or a continued focus upon deficits and a future filled with categories of disability and a remediation response to diversity. The vines can lead to independence or dependence. They can lead to a world where everyone's gifts are recognized and celebrated and where all are generous or it can lead to false charity, benevolence, materialism, and selfishness.

Today as I stand here, I am optimistic about where those vines will lead and the future of education. We will continue to make progress. As Cesar Chavez noted, *"Once social change begins it cannot be reversed. You cannot uneducate the person who has learned to read, humiliate the person who feels pride, and you cannot oppress the people who are not afraid anymore."*

Eleanor Roosevelt told us, *"The future belongs to those who have a dream."* Marsha Forest reminds us that *"We create our tomorrows by what we dream today."* It is an honor to stand before a room filled with people who have a dream and who will continue to sow their seeds well to make the future the best one the world can offer.

Thank you very much.

Rich Villa has been a general and special education teacher, as well as an administrator in one of the nation's first totally inclusive school districts. As the President of Bayridge Consortium, he provides training and consultation in areas such as collaborative teaming, creative solution-finding, systems change, and inclusion. Rich provides technical assistance to school districts, departments of education and advocacy groups across the country and around the globe.

Rich may be contacted at Bayridge Consortium in San Marcos, California by phone (760-761-4917) or e-mail <RAVilla@compuserve.com>

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Eleanor Helps Herself

BY ELEANOR BAILEY

I am 11 years old and in fourth grade. This year some little girls came to my school. I heard some people say "they have Down Syndrome." On a Saturday I asked my mom, "do I have Down Syndrome?" Mom said that I do.

I went to my bedroom and closed the door. I didn't cry, but I shut the door and was mad and upset. I didn't want to have Down Syndrome.

On Monday, I went to school. I told my teacher, Mrs. Karr, that I had an announcement to make. She gave me the microphone and I said: "I have two things to say. First, I have Down Syndrome and second, I am really scared that none of you will like me anymore."

My friends were really nice. They said they already knew that and they still liked me. Some of them cried. I got lots of hugs.

But I am still not happy! On Wednesday, my Dad and I got on an airplane and went to Chicago. On the airplane I listed to my Walkman. I have a song that goes, "Clang, clang, rattle, bing, bang, I make my noise all day." I thought that is what I can do. Even with Down Syndrome I can still make my noise.

We went to the TASH Annual Meeting. There were lots of really cool people there. We stayed in a big hotel. In our room there were two bathrooms. One had a shower and one had a bathtub. I made a sign that said "Girls" and put it on the door of the one with the bathtub. I didn't want my Dad to come in.

I took lots of baths. I thought if I took enough baths I could wash my Down Syndrome away. I also thought I would put hair spray on it, but my Mom and Dad won't let me have hair spray. I tried to put sunscreen on it because I thought that maybe then I wouldn't have to have it all of the time. But my Dad said that none of that would work.

I have friends that were at TASH. My really special friend is Tia Nelis [newly elected to the TASH Board]. She lives in Illinois. Tia has a disability but when she talks, people listen. They really listen. Tia is a leader and she really likes me. I told Tia that I have Down Syncrome. I was surprised when she said that she has always known that. She said she didn't care. She said that I am an important person and that Down Syndrome is not as important as being a wonderful person. When I grow up, I want to be just like Tia!

I have other friends at TASH who told me the same thing. I met a really nice person named Katie. Katie goes to college. She has Down Syndrome. I also talked to my other friend, Liz Obermayer. Liz has a new job and is moving to Maryland, which is a state. Liz has a disability, but she is a leader, too. She is also on the Board of TASH. Liz goes to lots of meetings and people listen to her, too.

I got my name from Eleanor Roosevelt. Lots of bad things happened in her life. I have read all about her. She was a leader. I also know about Rosa Parks, Martin Luther King, Nelson Mandela and Robert Kennedy. Lots of bad things happened to them, but they were strong and were leaders. My Dad says they made people proud of who they are and made them free.

I wish I didn't have Down Syndrome. But I do, and I am a person with lots of plans. When I wonder what to do, I remember my song. I will do what it says. I will go "clang, clang, rattle, bing, bang and make my noise all day." Even though I am sad, I know I can be as tough as anyone. That is what I want to do. Just be me.

This article was compiled from Eleanor's journal entries during the 1999 TASH Annual Conference. Reprinted with permission of Mouth.

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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TASH Newsletter

VOLUME 26 ISSUE NUMBER 4 APRIL 2000

OUR
SCHOOL
WELCOMES
EVERYBODY

INSIDE: Collaboration at Whittier High School; Standards Based Education Reform; and Effectively Educating Students with Challenging Behaviors

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

Stand For Freedom March

10 a.m. - 1:00 p.m. Wednesday, April 26, 2000
Harrisburg Hilton and Capital Rotunda
10:00 a.m. - Meet at the Hilton Hotel and march to the Capital
12:00 Noon - 1:00 p.m. - Rally at the Capital Rotunda

Please come to our Freedom March to celebrate the 600 people who have moved from institutions into community programs over the last two years. Come march with us for the 2,144 of our brothers and sisters who are still remaining in institutions across the State.

On April 26, Freedom Marches will be held all across the country in every state (sponsored by Self Advocates Becoming Empowered, the national self-advocacy group and co-sponsored by Pennsylvania Coalition of Citizens with Disabilities, Pennsylvania Developmental Disabilities Council; ARC, Montgomery; Visions for Equality). Be part of this historic national event.

We need your help and your support. We will have a Freedom Wall showing people's stories who have moved to the community. If you want to be on the Freedom Wall, call us at the Freedom Hotline, 1-800-867-3330.

Visit the Stand for Freedom Rally Web Page at www.speaking.org
Questions? Call our office at 610-825-4592.

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
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- **Don't forget to visit TASH's web site at http://www.tash.org**

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From the Executive Director

BY NANCY WEISS

For a field that defines itself by its commitment to inclusion and diversity, our willingness to polarize is notable. The response to the story of the Kelsos - the Pennsylvania couple who left their 10 year old son, Steven, at a hospital the day after Christmas - is a case in point.

A few months ago TASH started an internet discussion group called TASH Update. The group is a forum for TASH members to discuss the issues facing people with disabilities, family members and others who provide supports. The listserve is used to keep participants up-to-date on upcoming events, conference information, legislative action and for discussion of current events. (All TASH members are invited to join this discussion group. To join, go to: http://www.egroups.com/group/TASHUpdate or if you would like to receive only action alerts and legislative updates from TASH, go to: TASHAction-subscribe@egroups.com).

The actions of the Kelsos have been a hot topic on this list serve and elsewhere. One TASH Update participant, in response to a posting that called for more understanding of the stress parents are under, wrote:

"Somehow I must have missed the outpouring of similar sympathies and calls to avoid rushing to judgement when a father in Canada ran a hose from the exhaust of his truck to the cab—where his young daughter with cerebral palsy sat, until she inhaled her last breath. Somehow I missed a similar flood of support for the philosophies of Peter Singer, or Jack Kevorkian.

Regardless—TASH is an organization that is supposed to value and validate the perspective and experience of people with disabilities. This is a TASH discussion list. One would hope that value would carry into some attempt to at least strive to understand the perspective of Steven Kelso himself."

The Ragged Edge published a series of articles that were strongly critical of the Kelso's actions and called on the disability community to consider how Steven must have felt in being abandoned. One article began with this clear message: *"Dear fellow citizens who so naively believe that parents of disabled kids struggle with challenges the rest of us cannot possibly understand that you tell us not to judge Richard and Dawn Kelso for reaching the end of their rope and abandoning their severely disabled 10-year-old Steven at a hospital in another state: Go to hell."*[1]

Even this month's Redbook magazine included among its make-up and weight loss tips an article by a parent of two boys with disabilities that was strongly sympathetic to the Kelsos. The article says that the headlines about the Kelsos *"could hardly have come as a shock to any honest parent of a disabled child. Try 'Parents at the Brink of Collapse Don't Abandon Boy' for a real stunner."* The author goes on to characterize the Kelsos as "heroic" for taking him *"to a hospital where people are trained to care for him instead of loading him into one of those BMWs and heading for a cliff."*[2]

The Kelso's actions the day after Christmas last year raise important questions for the disability community. "Are there times when a parent's right to a "normal" life supercedes a child's right to a parent's care?" ... "And perhaps more to the point, do people in the disability community have a right to judge others against a set of standards that works for them?"

I have a friend who regularly reminds me (usually when I'm talking about not understanding another person's actions) that putting his head on another person's shoulders has never seemed to work for him. The Kelso's actions the day after Christmas last year raise important questions for the disability community. Are there times when a parent's right to a "normal" life supercedes a child's right to a parent's care? Is what constitutes "enough" support a personal decision that varies from family to family and can only be judged individually? Is it understandable to view the task of raising a child with disabilities as more of a burden than a joy? And perhaps most to the point - do people in the disability community have a right to judge others against a set of standards that works for them?

Because the actions of the Kelsos generated so much discussion that made us think, we have devoted a section of this *Newsletter* to various articles on the topic (see pages 25 - 28). We'd like to hear from you on this topic, either through the TASH Update, by e-mail to nweiss@tash.org, or by fax to 410-828-6706.

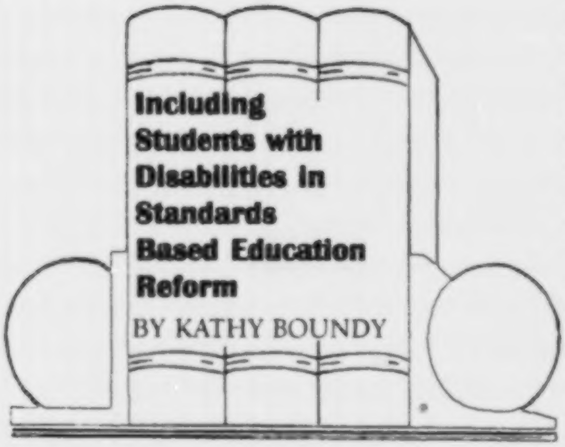
Footnotes:

[1] Josie Byzek. *Shame.* Ragged Edge, March/April 2000.

[2] Anne Mitchell. *When Love Isn't Enough.* Redbook, April, 2000. P.92

◆

Don't forget to send in your registration for The First International Conference on Self-Determination & Individualized Funding, Seattle, Washington, July 29-31, 2000. See pages 29-30 of this Newsletter for the Conference Registration Form.



Including Students with Disabilities in Standards Based Education Reform

BY KATHY BOUNDY

As states and school districts move toward full implementation of standards based education reform, a real opportunity exists for students with disabilities, their parents, advocates, and educators from preschool classrooms through school-to-work programs to ensure a high quality education for all students. In explicit legislative findings codified in the IDEA Amendments of 1997[1], Congress criticized the nation's education system for its more than 20 year history of low expectations of students with disabilities, its failure to disseminate what is known and has been learned, and its failure to implement research based practices for effectively educating students with disabilities.

While the IDEA Amendments of 1997, in fact, give students with disabilities few new rights, Congress clarified -- and in doing so, emphasized -- the rights of these students to receive high quality public education consistent with state education standards.[2] In addition, the IDEA Amendments stress the right of students with disabilities to participate fully in the general curriculum with their non-disabled peers,[3] and to be provided real opportunities to learn through specialized instruction, supportive services, supplemental aids and benefits, including services and training for teachers[4] to enable their students to meet, in whole or in part, the standards expected to be met by all other students. Students' individualized education programs (IEPs) are expected to be used, as they were intended, as critical tools to achieve educational goals: the IEP must be shaped by evaluations of disability-related educational needs and consistent with state standards, goals, objectives,[5] and state-of-the-art practices.[6]

Standards based education reform is designed to improve the quality of students' educational outcomes by identifying desired knowledge and competencies and aligning curricula and instruction to achieve this improvement. Critical to effective school reform is measuring whether schools and local educational agencies (LEAs) are making progress toward enabling all students to meet challenging state standards, and holding schools and LEAs accountable, in part, through public reporting requirements. Given the poor history of ensuring that students with disabilities participate in the general curriculum and receive the content provided all other children,[7] it is essential they be included in any standards based education reform initiatives. Their inclusion in standards based education reform is mandated under Goals 2000: Educate America Act, Title I of the Elementary and Secondary Education Act, the School-to-Work Opportunities Act and the IDEA Amendments of 1997.

Moreover, once a state has adopted this strategy for improving the quality of education, as evidenced, for example, by identifying and agreeing upon desired knowledge and competencies that students are expected to know and be able to do, aligning curricula and instruction with these content and performance standards, measuring whether LEAs are making progress in enabling all students to meet the challenging standards and holding states and school districts accountable, in part, through reporting requirements, then all these components must be applied to or include students with disabilities.[8] Any failure to provide students with disabilities the benefits of standards based education violates Section 504 of the Rehabilitation Act of 1973[9] and the Americans with Disabilities Act,[10] as well as section 1412(a)(16) of the IDEA Amendments of 1997.

Because states and school districts are required to establish a single set of standards that embrace all students,[11] they must develop a broad umbrella of standards that encompass supplemental educational needs, including, e.g., functional or independent living skills, of even those students with the most severe cognitive disabilities.[12] These students, who comprise a very small percentage of students with disabilities, may be unable to attain the levels of proficiency expected for all other students even with specialized instruction, related services, supplementary aids and services, individual accommodations or program modifications. Nevertheless, for a system to be inclusive of all students, it must adopt standards for all students, such as "habits of the mind" (e.g., persistence, attentiveness)[13] or independent living skills which subsume the widest range of abilities. Standards that address a wide range of ability, as all other standards, presumably can and should be broken down into components so that it is possible to determine whether students, including, in this case, those with significant cognitive disabilities, can demonstrate whether they are making meaningful progress. Also, including these students in field tests incorporating a broad range of standards reflecting a wide spectrum of learning is one way that states and school districts can identify and consider the educational needs of these students in the development of standards that embrace all students and reflect desired outcomes.[14]

Students with disabilities must be provided the curriculum and instruction necessary to allow them to make progress toward meeting the standards

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Including Students with Disabilities in Standards Based Education Reform

Continued from page 4

set for all students.[15] Many children with significant disabilities, including cognitive disabilities, are able to participate in at least portions of the general curriculum, when specialized instruction and related services and supplementary aids and services are provided, as needed.[16] To the extent that their curricula and instruction have been modified by their respective IEP teams, they will need to be aligned with those standards (and components thereof) that encompass their supplemental educational needs, as well as with the content and performance standards (or components thereof) for all students, also modified and adapted as necessary and appropriate by their respective IEP teams.[17]

* * *

Arguably, if states considered and addressed the educational needs of all students -- including those with significant cognitive disabilities -- when establishing standards for all children, there should be very few instances when it would be necessary to use an alternate assessment that measures different content.

* * *

Because all students with disabilities have a right to participate in State and school district assessments as well as accountability systems,[18] these assessments must include all students, regardless of the nature or severity of their disability. The use of accommodations and modifications, as necessary and as determined by their IEP teams, ensures that all students with disabilities have an equitable opportunity to learn and to demonstrate what they know and are able to do.[19] Indeed, most students with disabilities can participate in these large scale assessments, in whole or in part, if provided accommodations or other test modifications.

Sometimes accommodations are not enough for some students with disabilities to participate in state or district-wide assessments. Particularly, if accommodations are interpreted to preclude modifying the content of an assessment, students who could demonstrate progress toward meeting the standards established for all, if assessed differently, must be provided that opportunity. These students might be assessed using a performance assessment that measures progress toward proficiencies in the same standards but in a different way. For example, a student who possesses the ability but cannot demonstrate his or her actual level of proficiency or mastery of particular standards by using the written standardized test instrument (even with accommodations or modifications), but who could do so by building a model or using a computer program, must arguably be provided such an alternative (alternate) assessment that measures the same content standards being measured by the standardized assessment. On the other hand, an alternate assessment measuring different content may need to be developed for the limited population of students with such significant cognitive disabilities that they are unable[20] to demonstrate any measurable progress toward meeting even the broadest most basic standards, or parts thereof, using a standardized assessment or an alternative (performance) assessment designed to measure the same content differently. Arguably, if states considered and addressed the educational needs of all students, including those with significant cognitive disabilities, when establishing standards for all children, there should be very few instances when it would be necessary to use an alternate assessment that measures different content. Rather, these students would be administered the assessment, with such accommodations as needed, to determine their progress against the most basic components of standards established for all - i.e., a set of very broad standards that encompass the full range of abilities that have been broken down into components or benchmarks of learning.

Inclusion of students with disabilities in assessments can provide useful information about the system and the individual. The results of state and district wide assessments can serve as indicators that the curriculum, including any modified curriculum, is aligned with the full range of applicable standards, and that the curriculum is being implemented through effective instruction.[21] Individually, assessment results may also be used to provide feedback to teachers and parents about an individual child's educational strengths and needs, helping to shape instruction through review and revision of the student's IEPs.[22] Significantly, when such assessments are used in this way to improve instruction and learning and as a means of holding systems accountable, e.g., under Title I, Parts B and D of IDEA, and state education reform statutes, they cannot be used to impose 'high stakes' consequences (e.g., promotion or graduation) on students. To the contrary, poor performance is evidence that students have not received effective instruction and have not been provided adequate opportunity to learn. Nowhere is the evidence likely to be more clear than in the case of students with disabilities, especially students with cognitive disabilities, who have received inadequate and ineffective programming and instruction, and been inappropriately denied access to the body of knowledge contained in the general curriculum taught non-disabled children.[23]

Ultimately, students, parents, and advocates must be vigilant if states and school districts are going to be held accountable for improving educational outcomes for all students with disabilities. Students with disabilities will benefit from standards based education reform only when all students participate in a challenging general curriculum; educators, service providers and parents share high expectations that they can attain, in whole or in part, standards established for all other students; their teachers and providers rely on "state-of-the-art" knowledge and instructional strategies; and educators, parents, students and their advocates effectively use information gathered from the assessment process to inform student progress and systems improvement.

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2000 TASH Conference

"Moving the Edge"

December 6-9, 2000 ✣ The Fontainebleau Hilton Resort and Towers
4441 Collins Avenue, Miami Beach Florida 33140
Phone: 305-538-2000

TASH members, as individuals, advocates, families, and professionals, need to keep paving the way and stretching the boundaries for what is considered the "cutting-edge" in supporting people with disabilities to live the lives of their choice -- as integral and meaningful parts of the community.

Tentative Conference Agenda

Tuesday, December 5th
7:00 PM - 9:00 PM - Registration Open

Wednesday, December 6th
7:00 AM - 10:00 AM - Registration Open
9:00 AM - 4:00 PM - TASH Techs
3:00 PM - 7:00 PM - Registration Open
5:00 PM - 7:00 PM - Opening Reception

Thursday, December 7th
7:00 AM - 10:00 AM - Exhibitor set up
7:00 AM - 2:00 PM - Registration Open
8:30 AM - 10:00 AM - Opening Plenary
10:00 AM - 12:45 PM - Exhibits Open
10:30 AM - 12:45 PM - Breakout Sessions
1:00 PM - 2:15 PM - Roundtable /Box Lunch on the Grand Lawn
2:15 PM - 5:45 PM - Breakout Sessions
2:00 PM - 6:30 PM - Exhibits Open

Friday, December 8th
7:00 AM - 12:00 PM - Registration Open
8:00 AM - 10:15 AM - Breakout Sessions
10:00 AM - 7:00 PM - Exhibits Open
10:30 AM - 12:00 PM - General Session
12:15 PM - 5:00 PM - Breakout Sessions
5:00 PM - 7:00 PM - Gala 25th Anniversary Reception and Silent Auction in Exhibit Hall

Saturday, December 9th
7:30 AM -10:30 AM - Exhibits/Posters w/ Continental Breakfast
10:30 AM - 1:15 PM - Exhibit Hall Breakdown
10:00 AM - 1:30 PM - Breakout Sessions

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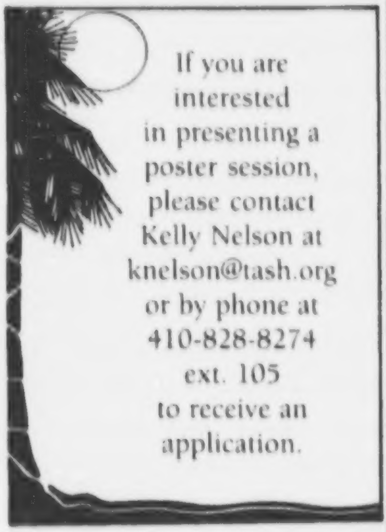
Mark your calendars now to be at the internationally acclaimed TASH Annual Conference, *"Moving the Edge."* Check our web site regularly <www.tash.org> for updates!

You spoke up...and we listened!

The conference planning committee has made some exciting changes for this year's conference. In response to the feedback received on the conference evaluation forms, TASH will be reducing the overall number of breakout sessions to offer a more "manageable" day of choices. The review board will be working harder than ever to select proposals that offer the greatest variety of interest areas, while continuing to provide the high quality presentations you've come to expect.

This year the registration fee will include two meals. On Thursday, December 7, the conference agenda includes a scheduled lunch break so that all presenters and attendees can attend a luncheon amidst the palm trees on the Grand Lawn. This special luncheon features roundtable discussions in a variety of topic areas. This event provides a great opportunity to discuss issues of interest with other TASH members as you enjoy your lunch with a lovely view of the beach, boardwalk and pool.

On Saturday morning, December 9, enjoy a continental breakfast while visiting an impressive array of poster presentations in the exhibit hall. This newly-added event will provide attendess a chance to speak one-to-one with presenters from around the world who have prepared an interactive presentation on a variety of topic areas. Feel free to take your time to visit with each poster presentation, as **there will be no breakout sessions scheduled during this exclusive exhibit and poster presentation time!**



If you are interested in presenting a poster session, please contact Kelly Nelson at knelson@tash.org or by phone at 410-828-8274 ext. 105 to receive an application.

Silent AUCTION

Interested in donating an item for TASH's Silent Auction? Contact Priscilla Newton, Director of Marketing, at 410-828-8274, ext. 102 or e-mail <pnewton@tash.org> Remember, the fair market value of your donation is tax-deductible!

• FREEDOM • CITIZENSHIP • FUNDING •
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FUNDING • FREEDOM • CITIZENSHIP • FUNDING
The First International Conference on
Self-Determination
& Individualized Funding

FUNDING FREEDOM CITIZENSHIP

The Westin Seattle
Seattle, Washington U.S.A.
July 29-31, 2000

Over 1,200 people from around the world are expected to participate in this groundbreaking conference on self-determination and individualized funding, including people with disabilities, family members, community advocates, professionals, service providers, researchers, administrators, and government officials. The conference will focus on sharing experiences and lessons from people's lives, demonstration projects, and research initiatives around the world. Conference attendees will also participate in consensus building activities to arrive at an "International Declaration," which will outline a shared view of the fundamental principles of Self-Determination and Individualized Funding.

For more information please visit the website http://members.home.net/directfunding/ or contact Denise Marshall at dmarsh@tash.org or 800-482-8274 x 103
From outside of the U.S. use the toll-free number 877-909-8274

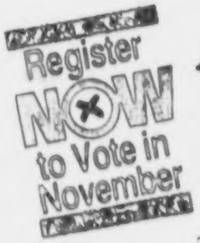
See pages 29-30 of this *Newsletter* for the Conference Registration Form.

Anchorage School District (ASD)

Seeking applications for '99-'00 and '00-'01 school years:

Special Education Teachers, Deaf Education Teachers, Interpreters for the Deaf, Speech Language Pathologists, Occupational Therapists, Physical Therapists, Adaptive Physical Educators, Audiologists, Blind or Visually Impaired Specialists and Psychologists.

Contact Carolyn Coe, ASD,
Special Education Recruitment,
Anchorage, Alaska 99519-6614,
call 907-742-4293, or send an e-mail to:
coe_carolyn@msmail.asd.k12.ak.us


Register
NOW
to Vote in
November

Are You Registered to Vote?

The National Mail Voter Registration Form is the one document that allows you to register to vote from anywhere in the United States. You can obtain the voter registration form from the Federal Elections Commission by going to http://www.fec.gov/votregis/vr.htm. You will need Adobe Acrobat Reader to view and print the forms. You may also obtain a copy by calling TASH at 410-828-8274 x104 or by sending an e-mail to <voterinfo@tash.org>

Each state has its own deadline for registering to vote. For more information and the registration deadline for your state go to: http://fecweb1.fec.gov/elections.html or call your state's board of elections.

Collaboration
at
Whittier High
School

BY MARY FALVEY, LORI ESHILIAN AND MARY JANE HIBBARD

Ricardo is a sophomore at his local high school and has qualified for special education services four of his years in school in the United States. He lives at home with his older sister, mother, and step-father. The family moved to Southern California from Mexico when Ricardo was 8 years old.

Ricardo has excellent social skills and is able to initiate positive interactions with others. He has some skills in using and understanding both English and Spanish. He has difficulty learning when being lectured to, or when reading and writing are the only forms of instruction.

At this time Ricardo is fully included at his neighborhood high school. His family is determined that he will participate in school activities, both academic and social, and that he be provided with supports when needed.

Ricardo is taking a math/science block, and a humanities block which consists of English and social studies, physical education class, and metal shop. He receives support in all his classes from a support teacher (formerly known as a special education teacher) or a paraprofessional from the special education department, who work collaboratively with the classroom teacher. Ricardo is provided with materials on tape or video, highlighted materials from his textbooks, and computer assisted instruction in order for him to understand the major content. With regard to math, he is provided with a calculator, a laminated copy of the formulas utilized, real life examples of when and how to use math skills, and a multiplication chart to assist his meaningful participation in class.

Ricardo is an active member of all of his classes, benefiting from the accommodations and adaptations created collaboratively by his support teachers, paraprofessionals, and classroom teachers. He also benefits from the use of differentiated instructional procedures used by all his classroom teachers, who share the disposition that all students can and should be learning meaningful age appropriate core curriculum in ways that make sense to them.

Ricardo attends Whittier High School (WHS), a large high school located in the East Los Angeles County. The school restructured using the Coalition of Essential Schools (Sizer, 1992) common principles in order to create a collaborative spirit and opportunity. The Coalition of Essential Schools are founded on the principles that the educational community must develop personalized and meaningful learning experiences so that all students can succeed.

Restructuring was first implemented in the lower grades, when 9th and 10th grade teachers and students reconstituted themselves into smaller teams. For juniors and seniors, attention also was directed toward career paths (e.g., establishing a Computer Academy) to assist students in identifying career opportunities; making connections between work, their community and the curriculum; setting educational and career goals for themselves; and internalizing the need for achievement in high school.

The teams also have divided their daily schedules into blocks of time. Instead of teachers teaching five periods each day, they teach two blocked periods per term plus one class outside of their team. By block scheduling integrated subject matter, the teacher/student ratio is reduced from approximately 180 to 90 students per teacher. Block scheduling has dramatically increased the time available for teachers to collaborate and has resulted in more personalized teacher-student time (Thousand, Rosenberg, Bishop, & Villa, 1997).

The elimination of the "special education teacher" label was considered critical to changing the perception that only "specialists" can work with students with disabilities. Thus, the high school selected the term "support teacher" to identify staff who, in collaboration with classroom teachers, supported (and coordinated services for) students eligible for special education. Support teachers take on a variety of collaborative roles with classroom teachers. They co-teach or team teach with content area teachers within heterogeneous classrooms and function as a support to all students, not just those who qualify for special education services.

To enable members of the team to work more effectively together, the administration scheduled a common preparation period and located classrooms in close proximity to one another. Teachers are more responsive to, and assume greater responsibility for students experiencing some difficulties because they have more time and opportunity to meet regularly

> The amount and type of collaboration and in-class support provided to classroom teachers is determined by the faculty team, which includes the student, and is based upon his/her individual learning needs.

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Collaboration at Whittier High School

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to share information about students' progress and challenges.

The "all-too-frequent" method of organizing students in secondary programs -- referred to as "tracking" -- has been intentionally decreased at this high school by eliminating what was previously called the "basic" track, the track identified for the students who were the least successful. All students, including those with disabilities, are required to enroll, participate, and learn in core college preparatory courses throughout their four years of high school.

Unlike traditional high school settings in which only those teachers in the same "department" or discipline work together, the math and science teachers work to create and teach a math/science block; and the social studies and English teachers work together to create and teacher a humanities block. In addition, the support teachers within each team work collaboratively with classroom teachers to write curriculum, plan lessons, and develop and deliver educational programs to meet the needs of students assigned to their team. These new groupings offer faculty opportunities to go beyond their initial area of expertise and certification and engage in "role release," the "giving away" of one another's specialty knowledge and skills so that all may become "generalists," more capable of teaching adolescents and young adults.

Support teachers quickly realized that their old way of matching students and special education support was clearly categorical (e.g., students with learning disabilities were assigned to teachers labeled Resource Teachers, students with low incidence labels were assigned to Special Education Class Teachers and rooms). As a result, in schools where inclusion is occurring, teachers might have two or three special educators interacting with them to support students with various labels in their class. This was an inefficient and confusing use of the special educator's time and expertise (Falvey, 1995). Therefore, WHS moved to a non-categorical system of support for students in which each support teacher is assigned to classroom teachers, and provides whatever support is needed for the students to be successful in those teachers' core curriculum classes.

Since all students are enrolled in core curriculum classes, this is where support is needed and provided. The additional support benefits not only those students identified as needing specialized services, but many other students who do not qualify for specialized services but who, nevertheless, experience their own unique challenges in learning. The amount and type of collaboration and in-class support provided to classroom teachers is determined by the faculty team, which includes the student and is based upon his/her individual learning needs.

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Thousand, J., Rosenberg, R., Bishop, K. D., & Villa, R. A. (1997). The evolution of secondary inclusion. *Remedial and Special Education,* 18(5), 270 - 284.

Mary Falvey is a professor of special education at California State University, Los Angeles, a former Executive Board member of TASH, and former President of Cal-TASH. Lori Eshilian and Mary Jane Hibbard are support teachers at Whittier High School.

New Legislation Introduced to Aid Families

Family Opportunity Act of 2000

Long time TASH friend Marcie Roth participated in a press conference recently to announce the introduction of S. 2274 - Grassley-Kennedy-Jeffords-Harkin FAMILY OPPORTUNITY ACT OF 2000. Currently, families must stay impoverished, become impoverished, place their child in an out of home placement or simply give up custody in order to secure the health care services their child needs under Medicaid. The Family Opportunity Act of 2000 would change this by allowing states to be able to offer Medicaid coverage to children with significant disabilities living in middle income families through a buy-in program.

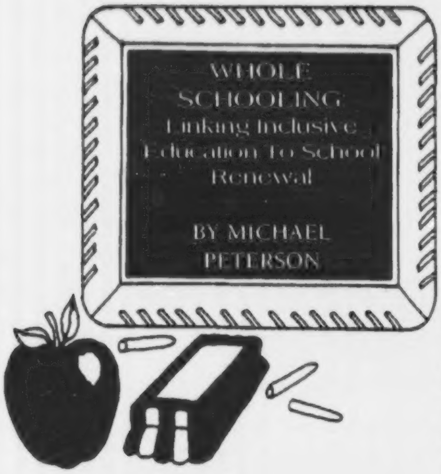
Marcie shared her experiences of struggling with the demands of providing the supports and health care needs for her children. "All my knowledge about systems didn't help my kids get the help they needed."

The Family Opportunity Act of 2000 is intended to address the two greatest barriers preventing families from staying together and staying employed:

1. Lack of access to appropriate services, and;
2. Lack of access to the advocacy and assistance services they need to help cut the "red tape" to meeting their children's health care needs.

Your Senators need to know how important this act will be to families caring for a child with a disability. You can contact them at www.senate.gov or the Capitol switchboard, 202-224-3121.

For additional information go to NPND's web site, <www.npnd.org>



WHOLE SCHOOLING
Linking Inclusive Education To School Renewal

BY MICHAEL PETERSON

Inclusive education is now an important international movement in which students with disabilities, and others identified as having "special needs" are moving back into the general education classes with support. Two major areas of challenge are obvious as we move forward.

First, schools are being challenged to structure their work differently. Over time, special education and other "special programs" were developed based on the presumption that students of vastly different academic, social-emotional, and sensory-physical abilities could not learn effectively together. Inclusive education challenges that assumption at a fundamental level. We are seeing schools use a range of strategies to facilitate instruction of very diverse learners: multi-age classes, multiple intelligences, differentiated instruction, cooperative learning, and more. We are also seeing a growing number of approaches and models of providing "support" for learning such as support teachers, aides, peer buddies, circles of support, and interdisciplinary teams.

However, the challenge works both ways. For those of us who started this journey with the needs of kids with disabilities in mind, we are now confronted with truly being a part of the school. In so doing, we are challenged to understand the complexities of issues we've only analyzed from the periphery previously: curriculum, learning, issues of poverty and race, and more.

In 1989, when Wayne State University's "systems change" grant for inclusive education began, I attended a meeting of project directors throughout the country. At one point I asked the question: "Who here understands best practices in general education instruction?" No one came forward! Although we've learned much since then, we've a long way to go.

For inclusive education to move ahead, we must be part of an overall effort to reform and renew schools. We must be part of the dialogue about standardized testing and curriculum, whole language versus phonics only, the challenges of urban school systems, tracking and untracking, the politics of unions, and the many other issues in which schools sit in the middle. We particularly have to think about inclusive schooling in the broadest sense. Segregation by race, socio-economics, and language tend to occur concurrently with segregation by ability. One is very often linked to the other. We can't afford to be only about "our kids" because, if we take that position, we perpetuate the continuance of schools that reject them.

There are many places in which to start school reform efforts, and work has begun in a few of them. We report briefly here on one such effort and invite others to join us in this critical work.

One School's Reform Efforts

In 1997, colleagues from Michigan and Wisconsin collaboratively developed a framework for improving schools that draws from and builds on the experiences of progressive school reform organizations nationally, particularly Accelerated Schools, Comer's School Development Program, Howard Gardner's Project Zero, and Sizer's Coalition for Essential Schools. Like the developers of these programs, we were concerned with several continuing facts of schooling:

1. Lack of supports of families and connection with communities.

2. Ongoing instructional strategies based on isolated, boring instruction that is disconnected from the real lives, family and community experience of students.

3. The need for democratic processes of decision-making in schools that empower students, families, teachers, and other school staff.

However, we have also been concerned about the lack of explicit attention to two major additional dimensions of schooling:

- The ongoing segregation of students with different learning styles and abilities into special programs for students with disabilities, those considerated "at risk", gifted, or those for whom English is not their first language.

- The lack of attention to the social and political context of schooling, specifically the increasing inequality in schools and communities, pressure to promote standardized testing that separates students, families, and whole communities by race, socio-economic status, and ability, and the growing focus of seeing the purpose of schools as preparing workers rather than promoting student-centered growth and learning.

The Five Principles of Whole Schooling

In an effort to address these critical factors in effective schooling, in 1997 we developed the Whole Schooling Model for School Reform that is based on the following five principles:

I. Empower citizens in a democracy. The goal of education is to help students learn to function as effective citizens in a democracy.

II. Include all. All children can learn together across culture, ethnicity, language, ability, gender & age.

III. Teach and adapt for diversity. Teachers design instruction for diverse learners that engages them in active learning in meaningful, real-world activities; develop accommodations and

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WHOLE SCHOOLING: Linking Inclusive Education to School Reform

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adaptations for learners with diverse needs, interests, and abilities.

IV. Build community & support learning. The school uses specialized school and community resources (special education, Title I, gifted education) to build support for students, parents, and teachers. All work together to build community and mutual support within the classroom and school, and to provide proactive supports for students with behavioral challenges.

V. Partner with families and the community. Educators build genuine collaboration within the school and with families and the community; engage the school in strengthening the community; and provide guidance to engage students, parents, teachers, and others in decision-making and the direction of learning and school activities.

What is the Whole Schooling Consortium?

The Whole Schooling Consortium is a network of schools, university faculty, teachers, parents, and community members whose goals are to:

✎ Promote Whole Schooling practices through research, professional development, and advocacy, particularly in schools that serve children from low income families and/or who are at risk.

✎ Build a grassroots network of schools, university faculty, and community members who can provide mutual support to one another.

✎ Link urban, suburban, and rural schools in promoting Whole Schooling practices.

✎ Develop a network of exemplary schools that are intentionally seeking to promote both equity and excellence in educational practices.

✎ Conduct research to understand best educational practices.

The Whole Schooling Consortium's efforts have grown out of the collaboration of general and special education faculty and school personnel. The Consortium is presently engaging in the following types of activities.

School Renewal through Whole Schooling

Schools can use the Five Principles as ways of organizing their school improvement and renewal efforts. A support team of external critical friends can provide assistance to school staff in this process. The Consortium is also inviting people in support organizations -- universities, state departments, intermediary school districts, and others -- to join in taking this work to the next level of development and implementation.

Networking Schools and Individuals

The Whole Schooling Consortium is composed of two types of members: (1) schools that see the Five Principles of Whole Schooling as the type of school they want to be; and (2) individuals who are committed to the Five Principles of Whole Schooling and are willing to work as part of the Consortium to promote its work.

The Consortium has an active and growing membership in multiple states and countries. The Whole Schooling Consortium facilitates networking of schools and individuals to provide support for ongoing school and personal growth and development. In addition, schools and individuals may more formally come together as a state, provincial, or local Whole Schooling Consortium to assist their efforts and contribute to the overall national agenda of the Consortium. As of February 2000, efforts are in process to affiliate schools and develop an active support team for school renewal using Whole Schooling as a model in the following states: California, Florida, Ohio, New Hampshire, New Mexico, and New York. Individuals from these and other states have joined the work of the Consortium at a growing rate.

Research

The Whole Schooling Consortium is intent on building a collaborative network of effective research to understand quality educational practices and promote their implementation in schools. At present two projects are in process.

1. Whole Schooling Research Project. In this federally funded research project, the Consortium is identifying six schools in Michigan and Wisconsin that demonstrate exemplary practices in Whole Schooling. The Consortium's goal is to study how practices associated with these principles interact with one another to support inclusion and learning of children with and without disabilities. The Consortium will highlight promising practices and describe its findings as this project continues.

Rather than looking in from the outside, or wishing someone else would 'include inclusion' in their school reform efforts, we can work with general education colleagues of like minds and create our own path. Others are engaged in similar work. To the degree we can work to take these next steps, while keeping the commitment and focus that led us into inclusive education work in the first place, the greater will be our impact.

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WHOLE SCHOOLING: Linking Inclusive Education to School Reform

Continued from page 11

2. Eastside Detroit Whole Schooling Cluster
Support faculty are involved in working with three schools on the eastside of Detroit in selected areas. While initially adopting Whole Schooling as the reform model, requirements by the funder led to adoption of Accelerated Schools as the leading model, and the Consortium is working in concert with regional staff in support of the schools. All schools have made a commitment to inclusive education, and the Consortium is conducting research regarding this school reform process to better understand how to engage schools in low income urban areas.

Professional Development
The Whole Schooling Consortium works to provide multiple opportunities for professional growth and development. In the originating states, Michigan and Wisconsin, the Consortium has held a summer institute for the last two years. The Education Summit represents an effort to provide a forum for organizing and professional development and will be held in June 2000 in Detroit.

Collaborative policy advocacy
The Consortium is joining with other groups, particularly the Rouge Forum, to engage in political and social advocacy for policies that make exemplary practices possible and to resist those that are destructive and harmful.

Towards the future
We have been amazed and a bit surprised at the positive response to the ideas and concepts of Whole Schooling. We believe this is because these ideas have hit a chord of response. Rather than looking in from the outside or wishing someone else would 'include inclusion' in their school reform efforts, we can work with general education colleagues of like minds and create our own path. Others are engaged in similar work. To the degree we can work to take these next steps, while keeping the commitment and focus that led us into inclusive education work in the first place, the greater will be our impact. We're happy to be part of this effort.

AN INVITATION

If you are an educator, parent, or community member who believes that schools should be inclusive, democratic, and authentic,
If you are tired of educational policies that hurt children and families,
If you want to connect and network with others who are doing the same to build a movement for quality schooling for all children,

The Whole Schooling Consortium invites you to join in its work. You may join as an individual member, a school, a university program or other organization. The Consortium will also work with you to organize a Whole Schooling Consortium in your area.

If you are interested, please contact:

Whole Schooling Consortium
c/o Wayne State University
217 Education Building
Wayne State University
Detroit, Michigan 48202
Jmpeterso@mediaone.net

The best source of information and contacts is the Consortium's web site. Contacts are posted on that site, as well as detailed information regarding ways to join in the work of the Whole Schooling Consortium.

http://www.coe.wayne.edu/CommunityBuilding/WSC.html

Michael Peterson is Professor in Teacher Education, College of Eduation at Wayne State University in Detroit, Michigan.

He is co-founder of the Whole Schooling Consortium, a network of schools, teachers, universities, and parents.

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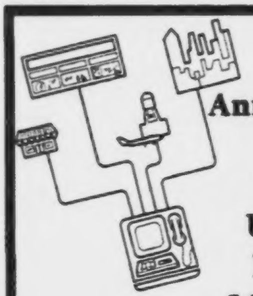

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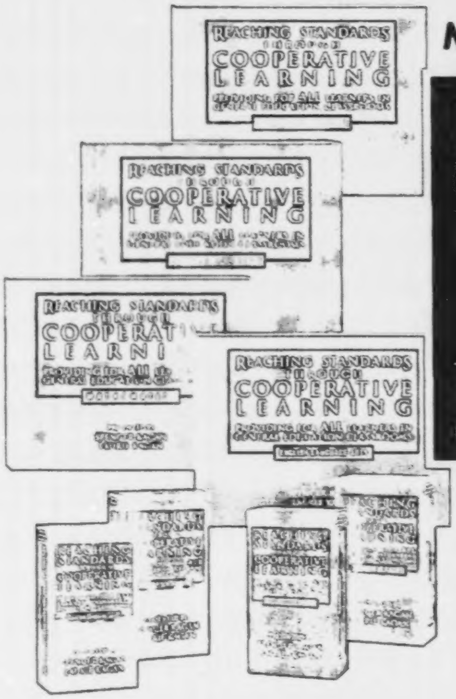

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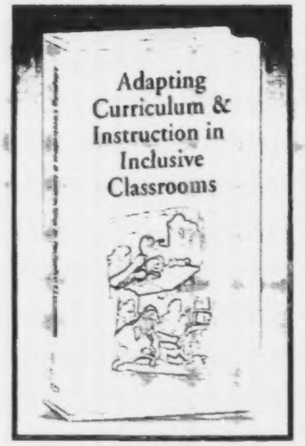

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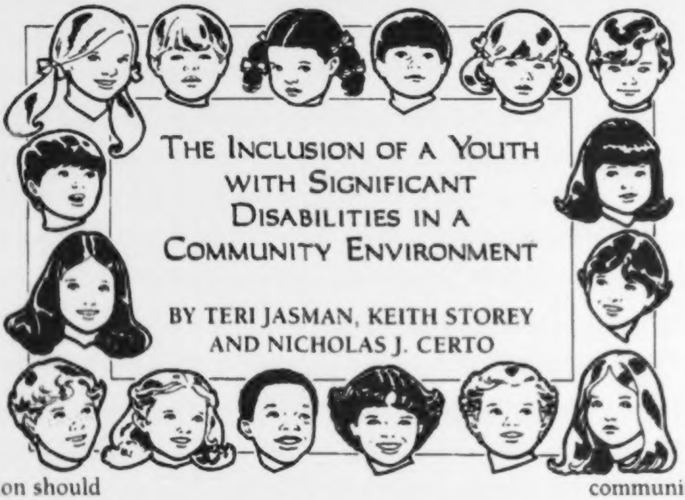

THE INCLUSION OF A YOUTH WITH SIGNIFICANT DISABILITIES IN A COMMUNITY ENVIRONMENT

BY TERI JASMAN, KEITH STOREY AND NICHOLAS J. CERTO

Research indicates that people with dual-sensory impairment benefit from instructional programs that encourage choice, autonomy, and participation with non-disabled peers and federal legislation supports this, as well. To most successfully support people with disabilities in integrated environments, the focus of participation should be on the activity rather than the level of performance. This way, all individuals are supported to participate to the best of their abilities, rather than being judged against one another.

In terms of learning in integrated environments, individuals who are labeled with deaf-blindness have a long skill acquisition learning curve due to the limited sensory input available to them. Natural supports can increase motivation and help to shorten this learning curve, while at the same time natural supports promote mutually beneficial relationship development and inclusion.

The purpose of this article is to provide an example of how community-based instruction, natural supports, partial participation and adaptations for communication strategies, as well as typical physical adaptations enabled an individual with deaf-blindness and intellectual disabilities to participate in a young women's self-defense class.

About the Participant

At the time of the study, Julie was a 14-year-old female with significant intellectual disability, limited sensory input due to deaf-blindness and delayed physical development. She attended a special day class at her local middle school. She had some residual vision and was totally deaf. Julie was non-verbal and used about 10 signs regularly and could recognize roughly 60. When prompted at home, she used an object communication board to choose preferences and predict upcoming activities.

Intervention

The intervention took place within a self-defense class for young women at Julie's local neighborhood community center. Julie was the only student with a disability in the class. Dependent measures were the frequency of communicative responses to four separate interventions, ranked from most to least intrusive: a) a group request from the teacher to the entire class, b) a signed cue given to Julie from a peer, c) a signed cue given from a peer to Julie paired with an object or tactile cue, and d) the researcher physically guided Julie hand over hand, demonstrating the correct response.

Phase I: Determining Preferences and Setting Goals

Julie's family and team of educators/ service providers met to have a MAPS (The McGill Action Planning System) meeting. Team members included Julie, her parents, brother, sister, teacher, paraprofessional, vision teacher, her case worker, her occupational therapist, physical therapist, a behavioral specialist, and an inclusion specialist (the first author). The team discussed her strengths and interests and established goals, such as increasing emotion signs by incorporating systematic reinforcement of signed protest and facilitating communication with the community members that do not use sign language.

The MAPS meeting identified a neighborhood community center that offered after- school classes as an ideal place to increase community involvement. A Self-Defense for Young Women ages 14 to 17 class was the most appropriate to incorporate these goals of increased communication and participation with Julie's peers and to increase self-determination through signing protest. There were five students in the class.

Phase II: Class Activities and Participant Involvement

Julie participated with prompts given from her peers and the researcher. The researcher showed the entire class and the two teachers proper prompting techniques. Prior to this intervention it was determined that without any physical prompts and tactile cues paired with signs, Julie did not initiate communication or respond to others. The data collection tool was designed to evaluate whether using adaptations would increase the frequency of communicative responses from Julie to her peers. The

[Skilled use] of natural supports can increase motivation and encourage participation of an individual with disabilities.

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THE INCLUSION OF A YOUTH WITH SIGNIFICANT DISABILITIES IN A COMMUNITY ENVIRONMENT

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instrument documented the occurrence of the following components of the cues: a) independent, b) ASL sign cue, c) tactile/ object paired with sign cue, and d) communicative responses prompted by hand over hand modeling.

There were sixteen trials (requests from a peer to Julie) over the course of each class session. In each trial, Julie had potentially 4 opportunities to make a communicative response. For example, with the teacher making a request to the entire class, if Julie did not respond appropriately with her classmates, one of Julie's classmates would sign a simple instruction to her (second opportunity). If Julie did not respond to the signed prompt from a classmate, a different classmate would sign the same request and additionally add either a tactile object prompt paired with the signed prompt. An example of this could be the sign "stand up" paired with a tap on the knee.

Phase III: Adaptations and Curriculum Modification

The specific physical adaptations developed were: a) blowing a whistle (substituted for shouting "No, get back!") and b) kicking a yellow ball (substituted for hitting a punching bag). The yellow ball adapted from the punching bag her non-disabled peers used provided a better contrast between objects in Julie's visual field. It also moved when she kicked it and took less strength to kick than the punching bag, resulting in a more meaningful experience for her.

Phase IV: Implementation of Instructional Programs

The modified curriculum, which was derived from a task analysis of the class activities, utilized other students to prompt, guide and initiate communication through the use of object cues, sign cues, and tactile cues. The instructional program consisted of the following lessons: a) Julie took off her glasses; b) Julie gave glasses to researcher; c) Julie received whistle from researcher; d) Julie put on her whistle; e) Julie felt mat and sat down; f) peer signed, "hi," to Julie and Julie signed, "hi," back; g) Julie immediately signed, "hi," to person to her left; h) researcher lightly shook Julie's shoulder continuously; i) peer gave whistle and signed to Julie, "When mad sign stop;" j) Julie signed stop; k) Julie was asked to feel target; l) Julie kicked yellow ball; m) Julie received whistle from peer to left; n) Julie signed something she did in class during "check-in;" and, o) Julie passed the whistle to student on left.

Julie was given up to four consecutive requests per trial. Her first opportunity to respond was when class instructors gave directions to the entire class. If Julie gave no response, a peer in her class gave a signed cue to her. If Julie did not respond to the sign cue, another peer would use the same sign cue and provide her with an object or tactile prompt. If Julie gave no response to object or tactile cue paired with a sign cue, the researcher would demonstrate the response by guiding Julie to perform the response with hand over hand assistance.

The class also had a processing component called, "check-ins." Sitting in a circle, the participants would pass the whistle around to indicate whose turn it was to talk. Students would share something positive about themselves. When it was Julie's turn she would be prompted to hold the whistle from the peer who had previously shared. Julie would share something with the group via signs prompted by the researcher, and pass the whistle on. They referred to this process as, "healthy bragging".

The other major task analyzed component of the self-defense class was setting limits. The class would role play situations of peer pressure and practice saying, "No," "Not now," or,"Stop." Julie was given options and opportunities to try the activities differently, but the content of signing "stop" was maintained. For example, she would try the activity with another student, do it sitting down, or take a break. She was respected whenever she protested. During these times of real-life protest, instruction was given from peers to Julie to sign, "Stop."

Results

Data were collected for eight days. There were 16 trials for Julie to respond on each of these days. For each trial, Julie had up to four opportunities to respond (i.e. independently, signed cue, object/ tactile paired with signed cue or hand over hand). Julie responded zero times out of 128 opportunities when she was given instructions with the rest of the class (independent cue). Upon second request, Julie responded three times to the 252 signed cues from her peers. On the third request when object or tactile cues were paired with signed cues, she responded 62 out of 381 opportunities presented by her peers. When Julie did not respond to tactile/object cues paired with signed cues, she was shown hand over hand by the researcher. Under this intervention, Julie responded to her peers 63 times out of 450 opportunities.

Discussion

The data indicate that Julie responded best to sign cues paired with objects or tactile prompting. A combination of adaptive communication strategies and adaptations to physically gain access to the environment was effective in increas-

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The Inclusion of a Youth with Significant Disabilities in a Community Environment

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ing communicative responses and participation.

To make inclusion a reality for many students with significant disabilities, it is imperative that adaptations are developed, systematically taught, and practical enough that teachers and non-disabled peers can accommodate to them easily. Challenges involved with making this a successful project included recruiting non-disabled peer support to teach appropriate prompting, training teachers to include the particular student with disabilities, and making adaptations simple to use so that any member of the class could easily give extra support.

A good placement and well-designed adaptations also helped to make this project successful. The staff was supportive philosophically of inclusion, they had support on-site, if needed, and direct instruction was given to the teachers and peers.

As the results indicate, Julie became less reliant on the researcher to model hand over hand responses as the class progressed. In addition, the data demonstrate that peer interactions using objects, paired with signed cues, increased as hand over hand demonstration decreased, depicting an inverse relationship. This suggests that natural supports can increase motivation and encourage participation of an individual with disabilities. As Julie's familiarity with her peers grew, her reliance on a specific support person faded.

There were occasions when Julie's behavior did have an effect on the rest of the class. At times she was disruptive and distracting to the class. These situations provided a real-life framework for the teachers and students in the class to learn about self-defense and the wider topic of themselves in an inclusive environment.

For example, one day in class Julie sat down, refusing to perform the activity of kicking the yellow ball. There was a temporary delay while the teacher, then a peer, then a second peer, and finally the researcher, prompted her to stand up. Eventually after four requests Julie stood up. Later, during the check-in toward the end of the class, one of Julie's peers mentioned that Julie's refusal seemed like a, "gutsy, strong stance; the kind of attitude, traditionally, girls are taught not to do." This illustrates some of the benefits of inclusion for people without disabilities, as well as an individual with significant disabilities. They learn about themselves in a wider social context; they learn about diversity and the feelings that go along with it; and, they learn about the give and take of an integrated community.

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School-linked Services

Reinventing Community in the Age of Globalization

BY WAYNE SAILOR

[This is part one of a two part article.]

The old maxim, "think globally, act locally" is very likely moving up on the hit bumper sticker charts. Its time is here, now. Most sociologists agree that the age of modern industrialization has ended but, until recently, few have agreed on just what has replaced it. How are we to characterize and therefore think about the present age? There is growing agreement and awareness that the modern industrial period has been replaced by globalization, a new concept that includes, but is bigger than, the idea of a global economy. There are profound implications of this transformation for the families, professionals and students who, for the most part, make up membership of TASH.

When TASH started in the 1970s, we were embedded in the structures of the modern age. The United States had evolved into a "welfare state." At the turn of the last century, human services were formed to assist people from other countries to successfully acclimate to the cultural and linguistic differences they would encounter in America. The growth of industry drove immigration policy and indirectly, welfare policy, to ensure a healthy new workforce in an expanding economy. The success of these programs in supporting economic growth led to federal policy supporting welfare systems through taxation. By the middle of the twentieth century, the gradual conversion of the U.S. economy from a manufacturing-based economy to a service-based economy helped to fuel the expansion and bureaucratization of these systems at both the federal and state levels of government.

Welfare systems expanded in scope and diversity of coverage fueled by categorization, labeling, prescriptive services and increasingly specialized professionals. Special education evolved, as one part of the welfare state; to provide necessary services and supports to students who displayed certain "disabilities" which could be helped by specially trained teachers. The civil rights implications of the American Constitution gradually led to the extension of these educational services to all children in the interests of "equity under the law." Then, PL 94-142 was passed in 1974 to guarantee that students with "handicaps" of all kinds would be entitled to services such as those received by students with minor disabilities. It took TASH to eventually break down the distinction between handicaps and disabilities by providing demonstrations that people with even very severe disabilities could work and live interdependently, the same as everyone else.

The process of inventing the welfare state was characterized by three "hallmarks" of the modern, industrial age: categorization; positivistic science; and professionalization. Special education is a marvelous case in point. Each label (ie. ED, SED, LD, SMH, etc.) implies specialized knowledge, discrete services and specifically trained professionals. For convenience of service delivery, specialized "places" were introduced in the context of education. Special education grew as new categories proliferated, fueled by the diagnosis and referral policies of school psychologists. American science actually comes in two flavors; positivistic ("quantitative" methods) and interpretivistic ("qualitative" methods). The term "positivistic" refers to the philosophical idea that there is rule-governed order throughout all aspects of the universe, and that our task as scientists is to discover the underlying laws that transform hypotheses into facts. The method of experimental control to test a prediction is favored, and since these operations can best be carried out by converting observed phenomena to numbers, positivistic science is sometimes referred to as "quantitative."

The second type of science employed by educational researchers is one favored largely by sociologists and anthropologists, and is called "interpretivistic" (sometimes "subjectivistic"). These scientists prefer to collect data from the perspective of the participant in the phenomenon of interest. Thus, the view of the "insider," supported by observations, documents and other sources of information can lead to understanding by building, for example, a comprehensive case study, or ethnography of the phenomenon of interest. Since interpretation is necessarily subjective, the methods of investigation are called "qualitative."

Since the welfare state grew under the dominance for medicine and the medical model for science (positivism), the other brand of scientific investigation, favored by sociologists, languished in the shadows. The process is nicely illustrated by the controversy over Facilitated Communication (FC). Sociologically-oriented special educators such as Doug Biklen reported successful applications of FC using qualitative methods. Behaviorists (positivistic orientation) set up experiments to test FC and largely

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Reinventing Community in the Age of Globalization

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concluded that only facilitators communicated, not the persons with autism who were being facilitated. Because the dominant paradigm for science produced a vote of "no confidence" in FC, it became de facto a gatekeeper, preventing access to FC despite documented successes reported from the other paradigm of science (arguably, the one most appropriate to the investigation of this particular phenomenon because of its low incidence of applicability). This process exactly mirrors what happens in medicine around holistic health care approaches and herbal remedies.

In effect, our paradigm of science determines what we decide we can "know" and therefore determines our choices among options in all areas of life. The paradigm of science for the modern, industrial period has been positivism. What will it be in the age of globalization?

The third hallmark of the industrial age has been professionalization. In the human services sector of the welfare state, the process of categorization and labeling has produced a similarly segmented array of highly specialized professionals, with each specialization yoked to its categorical "beneficiaries" (or, as John McKnight has reflected, "its victims"). In most universities the special education department recruits new faculty on the basis of categorical identity. Thus, the retirement of the "deaf-ed" professor means recruitment among applicants with that specialization. The universities, state education agencies, and professional guilds (i.e. CEC) work together to determine requirements for the certification of teachers that, in the modern era, have guaranteed perpetuation and expansion of that human sigmentation.

Now there are signs that all of that is changing. States are moving toward collapsing certification requirements across categories. University special education departments are merging with their brethren in general education. Education psychology is reinventing itself to produce healers and problem solvers instead of test-giving categorizers. When the federal government reauthorized IDEA, it permitted a measure of decategorization for the first time, up to age 9. Furthermore, it strengthened policies impelling inclusion and mandated aspects of Positive Behavior Support, all of which run counter to the strict categorical imperatives of the modern industrial service system.

The history of TASH has been to concentrate at the federal level for public policy. TASH members have been and continue to be active in reviewing and processing grants, in attending policy conferences in Washington and in attracting governent officials to TASH conferences. Through its chapter network, TASH has been similarly influential at the state government level in at least a subset of states. Is is not at all certain that, as we move into the age of globalization, concentration of effort at federal and even state levels of government will produce the same results for persons with severe disabilities that it has in the past.

In the industrial age, government policy was directed to the national interest. In the age of globalization, multinational corporations are in the drivers seat and policy is increasingly directed to corporate rather than national interests. Governments at the federal level of wealthy nations are "paring down" national interests, particularly welfare, in order to position themselves as "lean and mean" to attract multinational corporate investment. Within the U.S., the same is happening at the level of state government. Kansas, for example, privatized its child welfare system precisely to trim its state budget in order to appeal to multinational corporate interests seeking to build distribution sites near the center of the country. The health, educational and well-being of the children involved is rapidly becoming a local issue rather than one that can be addressed at the levels of state or federal policy.

So as TASH members, what can we achieve locally? First is to make common cause with others in the same situation. "Common cause" in this sense means joining with, and supporting the efforts of, others pursuing a local humanistic agenda, while educating them about TASH issues affecting persons with disabilities. People concerned with conservation, preservation of the arts, air and water quality, smart growth (of real-estate development), second-hand smoke and other health hazards and, eventually gun control, are likely to have constituencies in common at the local, community (or neighborhood) level. The TASH agenda of choices, jobs, self determination inclusion and supported life in the community is consistent with the agendas sought by many other groups, particularly those concerned with the health and well-being of children and persons who are victims of poverty. Election to school-boards, county commissions, city councils, neighborhood political action groups, etc., can help move a TASH agenda through political action and common cause at the local level.

Secondly, TASH members can pursue an inclusion agenda through the schools on the basis of gain for all, rather than on the basis of federal issues such as LRE policy and civil rights. TASH members and special educators have developed major educational innovations that are needed now for all kids, not just those with severe disabilities. Positive Behavior Support is a wonderful case in point. Recent applications of school-wide PBS in Oregon, Hawaii and Kansas City are showing that inclusion of special needs students in general-ed settings gets special education resources in position to be of benefit for all kids. Through problem solving in group action planning around inclusion, general-ed kids learn citizenship, democratic practices and appreciation of diversity.

Finally, TASH members can work to link schools, community services and families

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in functional productive partnership arrangements. School-linked service integration arrangements, such as represented by Beacan Schools, Full Service Schools, Community Schools and so on afford opportunities to de-fragmentize the categorical service systems of the past, and to reinvest deployment of resources to benefit people with special needs where they, not the professionalized service agencies, call the shots.

Part II of this article will appear in the May issue of the TASH *Newsletter*, and will contain some examples of types of localized partnerships that work for special-needs populations and describe how these can get started.

Wayne is Director of the University Affiliated Program for the University of Kansas, Lawrence Campus. He is a Professor in the Department of Special Education, a life-long TASH member and former TASH president.

His current research interests are linking schools, community services and families in partnership arrangements; and Positive Behavioral Support as the basis for school-wide discipline. Wayne can be reached at 785-864-4950 or at w-sailor@ukans.edu.

Standards Based Education Reform

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Kathleen B. Boundy is the co-director of the Center for Law and Education (Boston, Washington, D.C.) where, as an attorney, she represents low-income students, including students with disabilities. This paper is a revision of a paper that originally appeared in the November 1998 newsletter of the National Transition Network. The author acknowledges the support and assistance of her colleagues at CLE, especially Attorney Eileen L. Ordover; she also acknowledges the assistance of Nancy J. Zollers, Ph.D. However, the views expressed are those of the author and do not necessarily reflect those of CLE, as an entity, or those who have generously assisted her in thinking through the issues addressed in this article.

FOOTNOTES

1. 20 U.S.C. 1400(c)(4) (1997).
2. 20 U.S.C. 1401(8), 1412(a)(1).
3. 20 U.S.C. 1412(a)(5)(A), 1414(d)(1)((A)(i)(I), (ii)(I), (iii)(II),(III), (iv).
4. 20 U.S.C. 1414(d)(1)(A)((iii).
5. 20 U.S.C. 1414(d)(1)A)(i)(I), (ii)(I),(iii)(I).
6. 20 U.S.C.1412(a)(14) incorporating by reference 20 U.S.C.1453(c)(3)(D)(vii), regarding "State-of-the-art" requirement.
7. 20 U.S.C. 1400(c)(4), (5)(A)-(E)(i); see also, Back to School on Civil Rights: Advancing the Federal Commitment to Leave No Child Behind, National Council on Disability, January 2000.
8. A more detailed discussion of this topic can be found in "Students with Disabilities and the Implementation of Standards-Based Education Reform: Legal Issues and Implications." Eileen Ordover, Kathleen B. Boundy and Diana C. Pullin, prepared for Committee on Goals 2000 and the Inclusion of Students with Disabilities, National Research Council, National Academy of Sciences, June 12, 1996.
9. 29 U.S.C. 794.
10. 42 U.S.C. 12132.
11. Goals 2000: Educate America Act, 20 U.S.C.5802(a)(1), 5881(15), 5882(a), 5886(c),(n); Title I, 20 U.S.C. 6301(b)(3), 6312(b)(4), 6315(b)(3)(1); 20 U.S.C. 1412(a)(16), 34 C.F.R. 300.137(a)(2); State education reform statutes.
12. 20 U.S.C.1412(a)(16), (17); 34 C.F.R. 300.137(a)(2), (b), 34 C.F.R.300.138; 34 C.F.R. 104.4(b)(1), 104.333(b)(1)(i), 28 C.F.R. 35.130(b)(1).
13. Sizer, T. (1992), Horace's School: Redesigning the American High School, Boston: Houghton Mifflin. All students need to learn different types of skills, including habits of the mind (such as inquisitiveness, diligence, tolerance, collaboration, and critical thinking), content area knowledge (science, social studies, language arts, the arts, etc.), and basic academic skills such as reading, writing and mathematics.
14. Because virtually all states have by this time adopted standards and few, if any, have considered appropriate educational goals for students with the most severe cognitive disabilities, it may be necessary for States to supplement their standards by adopting a set of standards that incorporate the widest range of ability.
15. 20 U.S.C. 1412(a)(5)(A), 1414(c)(iv), (d)(1)(A)(ii)(I),(II), 34 C.F.R.300.347(a)(2), (3), (7), 300.552(2); 34 C.F.R. 104.4(b)(4), 104.33(a)(b)(1), 104.34(a); 28 C.F.R. 35.130(b)(1)(ii)-(iv), (b)(2), 35.130(d); 28 U.S.C. 35.130(b)(3).
16. 20 U.S.C. 1414(d)(3),(A),(B)(iv), (v), (C), (4), 34 C.F.R. 300.346(a) - (c),(d)(2).
17. See, Title I, 20 U.S.C. 6314(b)(1)(B), (H), 6315(c)(1)(A), (B), (D), 6315(c)(2)(B); Goals 2000, 20 U.S.C. 5802(a)(1), 5886(c)(1)(C), 6065(b); 20 U.S.C. 1401(8) (B), (C), 1412(a)(2)[definition of FAPE]; 20 U.S.C. 1414(d) [participation in the general curriculum]; 20 U.S.C. 1412(a)(5)(A); 34 C.F.R. 104.34(a); 28 C.F.R. 35.130(b)(2), 35.130(d) [participation in the regular education program and setting]; and the right not to be discriminated against under section 504 and the ADA [34 C.F.R. 104.33(a)(b)(1), 34 C.F.R. 104.4(b)(4); 28 U.S.C. 35.130(b)(1)(ii)-(iv), 35.130(b)(3)].
18. 29 U.S.C. 794, 34 C.F.R. 104.4(b)(1)(i)-(iii), 104.4(b)(2); 28 C.F.R. 35.130(d); 20 U.S.C. 1412(a)(17), 34 C.F.R. 300.138.
19. 20 U.S.C. 1414(d)(1)(A), 34 C.F.R. 300.347(a)(5), (7).
20. Such determination would have to be made in a valid, reliable manner consistent with testing principles.
21. See Goals 2000, 20 U.S.C. 5886(c)(1)(B)(i), 6065(a), (b); Title I, 20 U.S.C. 6314(b)(1), 6311(b)(3), 6317(c)(1), 6315(b)(1)(B), (c)(2)(B); 20 U.S.C. 1412(a)(16)(B) - (D), 1412(a)(17)(B); 34 C.F.R.300.137, 300.138(a), 300.139.
22. See Title I, 20 U.S.C. 6311(B)(3)(), (I), 6314(b)(1)(H); 20 U.S.C.1412(a)(17)(B), 300.137(b), 300.139, also IEP review and reevaluations at 20 U.S.C. 1414(d)(4)(A), 34 C.F.R.300.343(c), 300.347(a)(7), 300.350; 34 C.F.R.104.4(b).
23. 20 U.S.C. 1400(c)(4).

Acting on a Vision:
Agency Conversion at Katahdin Friends, Inc.

BY PAM WALKER

Since the mid-1980s, Katahdin Friends, Inc. (KFI), located in the town of Millinocket, in rural north central Maine, has transformed its supports for people with developmental disabilities from those that promote segregation to those that promote community inclusion and membership. KFI began in 1962 in response to the requests of parents whose children with developmental disabilities were not being served in the public schools. In the mid-1970s, the agency began offering adult vocational services for those who were no longer in school. For the first 15 years of its existence, the agency operated a number of facilities -- a segregated preschool and a special purpose school, and later a sheltered workshop and a day program.

Beginning in the mid-1980s, the agency embarked on a path toward conversion from facility-based to inclusive services. Since that time, they have transformed the preschool into an integrated preschool; and, they closed the special purpose school, transferring children into regular public schools. KFI closed both the workshop and the day program, opting instead to support people in community jobs and other meaningful, integrated daytime activities.

Before they began the closure of the workshop and day program, the adults they served lived primarily with their families or in foster homes. The process of closing the workshop and day program led KFI to examine other aspects of the lives of people they supported. As a result, the agency began to offer different types of residential supports (e.g., as alternatives to family or foster homes, for those who so desired). Over time, they have developed the capacity to provide intensive residential supports to enable a number of people with very significant disabilities to move out of institutions and into their own homes.

This article is part of a series of reports designed to document innovative daytime and supported living practices. It is based on a site visit in March 1998; it reflects the agency at the time of the visit. At that time, the agency provided supported living services to 22 people, and day services to 14 individuals.

STRATEGIES AND LESSONS FROM AGENCY CONVERSION

Conversion did not happen all at once, but was a process that spanned several years (e.g., from the mid-1980s to the early 1990s). Over the course of their conversion, the agency used many different strategies and learned many lessons about the closure of facilities and the development of individualized community supports. Some of these are discussed below.

Continual decision making based on values and vision

Having an agency mission and values that support inclusion are not enough in themselves. In the process of conversion, KFI held every decision, whether large or seemingly small, up to the mission and values. Thus, many decisions, both large and seemingly small, contributed to the conversion at KFI. One staff member expressed that she felt their success was based on being able to take advantage of these decision points as opportunities for change: "We really changed by using opportunistic incrementalism. When we had decisions to make, we went in the direction of our philosophy."

The decisions and changes were not easy, and agency staff struggled at many different times. "When we moved our day program from one building to another, should we take the soda machine? It was important to some people, but we didn't move it because we wanted people to use the community."

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Acting on a Vision: Agency Conversion at KFI, Millinocket, Maine

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Later, in 1989, they made the decision not to do subcontract work. This was also a very difficult decision. "It was a heart-wrenching discussion. But we didn't want to be the employer any longer. We asked, 'what is the value of this subcontract work?' It is filling time. What a terrible reason to continue."

Agency conversion, then, was a result of a clear vision and many combined decisions. They recognized that they would not be able to implement an ideal vision -- that there would be trade-offs and compromises involved. In light of this, they advise others in the midst of agency change to at least recognize and acknowledge the compromises. As one staff member put it, "Know when you're compromising; but don't start with a compromise."

In the coming years, KFI will be faced with increasing pressures to expand its services in order to get more revenue for the agency. In addition, because they have a reputation for delivering quality services, increasing numbers of families and people with disabilities are seeking KFI's services. The challenge for the agency will be to continue to hold up each decision to its values, so they can maintain their capacity to be an individualized, flexible, and responsive organization.

Finding and/or working to create flexibility within funding and regulatory systems

In this day and age of tight fiscal environments, it is not easy for any agency to support people with significant disabilities in individualized ways in the community. The approach of KFI has been to make plans with people, with a commitment to figuring out how to implement them, rather than letting the planning be driven by fiscal and regulatory issues. At the same time, increased flexibility within the system can greatly facilitate the provision of individualized community supports. Thus, KFI staff have worked on their own and in collaboration with others to find and create flexibility within the system in many ways, including those described briefly below:

❖**Obtaining supplemental funding**. In order to close the workshop, they were helped initially to begin community employment services by a state grant. Later, federal and state grants (e.g., a federal grant to promote transition from school to adult services; a state organizational change grant) also helped them expand their community supports.

❖**Retaining some flexible funds**. It is sometimes tempting, and sometimes necessary, for an agency to trade in its state dollars for Medicaid dollars. However, the state dollars generally allow a much broader range of supports. Thus, KFI has been conscious about keeping a good balance of both Medicaid and state funds.

Through its conversion, KFI aimed to move from services that promoted segregation or simply community presence, to services that assisted people to lead rich, meaningful lives in the community. Their experience illustrates that such organizational transformation is possible.

❖**Obtaining bridge funding for conversion**. During the process of conversion to community services, it is often important for agencies to have some bridge money available (e.g., to help with start-up costs for supports for people in new settings, etc.). KFI was able to arrange with the state Bureau of Rehabilitation to obtain an equivalent fee-for-services amount for people they supported, even if the specific units of service decreased, which provided some bridge funding for the agency transition.

❖**Negotiating with the state for more flexible hours for daytime supports**. Initially, daytime supports for people were all within the 9:00 A.M. to 3:00 P.M. time frame. Staff at KFI identified the problem as follows: "The state was defining daytime services as a day; we requested them to define it in terms of hours, so we could do things at any time." The state agreed to this change. Now supports can be provided anytime between 7:00 A.M. and 9:00 P.M. KFI staff and the people they support now have greater flexibility in figuring out individualized daytime options.

❖**Combining residential habilitation and day habilitation funding**. With combined funding, there is no separation between day and residential staff. It also makes it easier to provide flexible daytime supports (e.g., without people having to be out of their homes for specific hours every day).

KFI's ability to find this flexibility is, in part, enhanced by its positive, collaborative relationships with others, as described below. While they have been very creative in dealing with fiscal and regulatory issues, staff at KFI acknowledge that the system still does not provide incentives for the kind of work they are doing. Thus, they face the ongoing challenge of struggling against systems barriers and disincentives.

The importance of collaboration

KFI's collaborative relationships with many individuals and organizations is a great asset. They have identified people at the state level who are creative and flexible in their use of the Medicaid waiver. In addition, they have cultivated positive relations with a variety of state-level people, based in part on KFI's reputation of accomplishing what it commits to, and doing so in a quality manner.

In addition, the connections that KFI staff have forged with other disability

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Acting on a Vision: Agency Conversion at KFI, Millinocket, Maine

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services agencies enhance the support that is provided to people. For example, their close collaboration with people in the mental health field is critical to their support of people with developmental disability and mental health labels.

Recognition that space defines what you do; thus, the determination to proceed with closing the facility, despite their own uncertainties and lack of answers for everything. Administrators at KFI were aware that if they maintained special, separate places, they would end up using them. They realized that they could not effectively promote inclusion with a dual system of services. Thus, they made a commitment to follow a path toward complete facility closure.

Doing this was not without some risk. Some vocal people in the community were upset by the closure of the facilities. Staff also worried about their own jobs, wondering if closure of the facilities would lead to elimination of their jobs altogether. In addition, when they made the commitment to closure, they didn't know all the answers as to how it was going to be accomplished. However, along the way they spent time learning from others who had also closed facilities, as well as learning from their own actions and experiences. While staff at KFI have learned a tremendous amount over the last several years, a strength of the organization is that they do not consider themselves as having all the answers now, but see themselves as continually learning about the people they support and how best to assist them.

Looking at People's Lives as a Whole
The initial primary focus on helping people work in the community led, over time, to a broader focus on looking at other aspects of people's lives, including supported living services:

> *"After getting out of the sheltered workshop business, we were still running the day center. But, we said, 'why do people have to come here? Because they don't live in their own homes.' So, we began working to help people have their own homes, and provide support to them out of their homes, rather than a facility."*

KFI also broadened its supports to encompass integrated daytime activities and involvements, in addition to employment. They recognized that people who were not working sometimes sat around all day with nothing meaningful to do, either at home or in segregated day programs. Additionally, those who worked most often worked part time, and again spent much of the rest of the day in isolation or boredom.

Overall, KFI has helped has helped many of the people that they support to develop diverse community connections and relationships. At the same time, as in many other agencies that give priority to this, some of the people they support are still relatively isolated socially. Thus, a challenge is the ongoing work of relationship-building and community-building.

At the same time, this focus on a wide variety of daytime involvements does not diminish the importance that KFI places on helping most people find paid jobs. Agency staff have been successful at finding paid work for many of the people they support. However, there are also a number of people who they support who would like jobs but do not have them yet. Thus, a continuing challenge for the agency is to expand their capacity to find jobs for others who are seeking them, in ways such as creating additional job development positions, and/or encouraging all staff to see job development as part of their role.

Keeping a Focus on Relationships
It is key that a focus on relationships pervades all of the work of KFI. This includes relationships of many types:

❖**Relationships between staff and the people they support.** The relationship between staff and the people they support is seen as being critical to the support. Overall, KFI staff appear to have close, committed, trusting relationships with those they support. At times when there is not a good match, changes are made in order to find a better match. KFI staff recognize the challenge of not becoming the sole safety net or social network for a given individual. They are concerned both about some people that they support becoming overreliant on staff, and about some staff having trouble letting go of people. This does not prevent them from encouraging staff to build close, caring relationships. However, it reminds them of the need to continually work to expand people's networks beyond staff, as well.

❖**Staff relationships with families.** KFI staff strive to help people maintain relationships with their families, and have helped some people reconnect with family members who had been out of touch for many years. In addition, KFI staff feel it is important that they try to have positive, working relationships with families. While they have done this in many instances, they also feel, at times, that they could do more in terms of working with families and involving them in planning and other aspects of people's lives.

❖**A wide variety of relationships for people who are supported by KFI.** Some of the people that KFI supports had long-term, close friendships with

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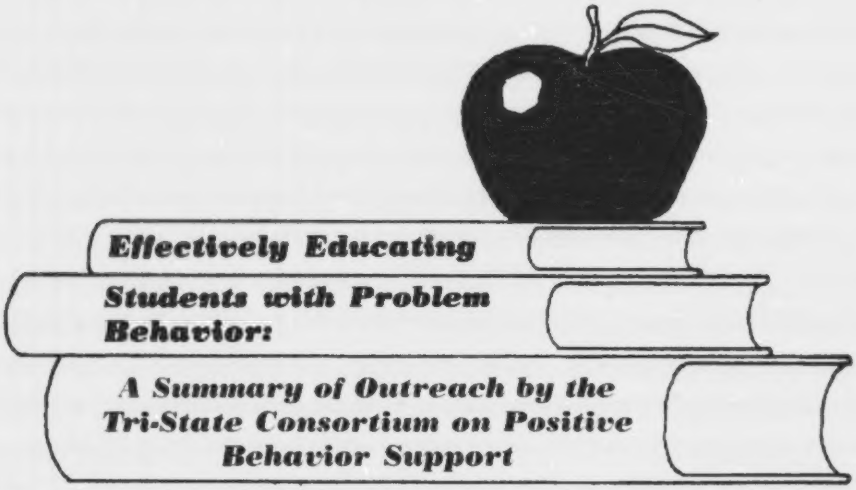

Effectively Educating Students with Problem Behavior:

A Summary of Outreach by the Tri-State Consortium on Positive Behavior Support

BY TIM KNOSTER, DON KINCAID, JENNIFER McFARLAND, CAROL SCHALL, ANNE MALATCHI, PATRICK SHANNON, JUDY HAZELGROVE, JEANNINE BRINKLEY, and JOSH HARROWER

Effectively educating students who present behavioral challenges has long been a problem for schools. In fact, problem behavior has been cited as one of the most common reasons as to why students with disabilities are removed from typical home, school, and work settings. To address this challenge, educational teams in Pennsylvania, Virginia, and West Virginia have been increasingly participating in an effective problem solving approach referred to as "positive behavior support" or "positive approaches." The Tri-State Consortium on Positive Behavior Support has served as a catalyst to this outreach.

The Tri-State Consortium (simply referred to as the Consortium) is a federally funded project operated by the Pennsylvania Department of Education through its Instructional Support System of Pennsylvania. The Consortium is a multi-state Outreach Project funded through the U.S. Department of Education Office of Special Education Programs.

As was highlighted in the November 1999 Edition of the TASH *Newsletter*, positive behavior support in school programs represents an empirically-based, problem solving approach that matches supportive strategies to the needs of individual students, their families, and others across school, home, and community settings. The Consortium represents a three-state partnership reflective of a natural evolution of collaborative endeavors supported through the Rehabilitation Research and Training Center (RRTC) on Positive Behavioral Support, which is funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education. Consistent with the RRTC, the Consortium has employed the following central tenant and operating assumptions from the inception of its outreach endeavors which began in the Fall of 1996:

Central Tenant	**Problem behavior results from unmet needs**	
Four Operating Assumptions	**1)**	**Problem behavior is context related**
	2)	**Problem behavior serves a function for the student**
	3)	**Effective interventions are based on a thorough understanding of the student, his or her social contexts, and the function of the problem behavior**
	4)	**Support must be grounded in person-centered values that respect the dignity, preferences, and goals of each student along with his or her family.**

Outreach Efforts to Date

The Consortium has engaged over these past three years in a number of outreach activities within the three state region. Additionally, collaboration between the project and other kindred endeavors in other regions of the United States has occurred. The development and implementation of behavior support plans for individual students has served as the focal point of outreach. However, energies have also been directed towards outreach on building based approaches that are compatible with individual student systems of behavior support. It is also noteworthy that outreach by the

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Consortium has occurred with teams educating students that reflect a broad spectrum of diversity (inclusive, but not exclusive of students with disabilities). The following is a snapshot of outreach activities to date by the Consortium:

Outreach by the Tri-State Consortium, 1996-1999

Information Dissemination:	16,936 recipients
Training:	15,128 participants
Technical Assistance:	1,291 recipients
Student Centered Teams:	Over 400 across schools in the Consortium
Additional Activities:	Developed user friendly training materials; Developed a synthesized training curriculum; Provided policy reviews and guidance

Core Components of Training/Technical Assistance Curriculum

One of the initial steps taken by the Consortium was to reach agreement on a synthesized training curriculum. This served as the project's initial activity in 1996. The process of generating this curriculum was relatively smooth as a result of the commonly shared training and support provided to each of the project's three states in previous years through the RRTC. The Consortium's curricula is consistent with the RRTC and is comprised of seven core components:

♦Team Forming and Establishing Goals for Intervention
♦Collaborative Approaches to Problem Solving
♦Conducting Functional Behavioral Assessments
♦Designing Multi-component Individualized Support Plans
♦Implementing, Monitoring, and Adapting Support Plans
♦Evaluating Impact of Positive Behavior Support
♦Imbedding PBS within and Across Systems

In addition to implementing this curriculum, the Consortium has also studied the process of supporting school-based teams across a variety of settings (i.e., elementary, middle, and high schools in rural, suburban, and urban communities). As a result of our endeavors, we have come to realize that it is essential to understand the needs of support team members and the demands placed upon them within their roles and settings in order to efficiently support teams to comprehensively design and implement individualized support plans. Focus on both the content and process of positive behavior support have served as cornerstones in our project's activities in evaluating the impact of outreach efforts.

> *Constructive behavior change still serves as the foundation on which positive behavior support is evaluated. However, it is important to realize that there are times when an individual student's behavior does not immediately change, but his or her environment is positively altered by the support activities of the student's team. In other words, a child's behavior may remain the same, but the child's teachers and/or parents have learned methods to more efficiently de-escalate crisis situations.*

Evaluating Impact of Outreach

Habilitative behavior change has served as the focal point of outreach through the Consortium. However, over the course of the past few years, we have become increasingly aware that to comprehensively assess impact requires attention to a wider range of factors than isolated behavior change. We have come to refer to this wider range of factors as "quality of life" or "ecological" outcomes. In light of this, the Consortium has focused energy on identifying and measuring a set of broader outcomes with students, families, and teams that include emotional, material, and physical well being; interpersonal relationships; personal growth and development, self-determination; social inclusion, and exercising individual civil rights and responsibilities.

Our efforts in this regard represented an extension of work initiated in West Virginia by the Life Quilters Project in 1989. Through collaboration, the Consortium further refined those initial efforts in a manner that cross references assessment procedures and data sources in a more time efficient manner. As a result, the Consortium's current approach to measuring impact addresses decreases in problem behavior, increases in alternative skills, positive side effects, improvements in quality of life, team member satisfaction, and improvements in general health and well being. To assess impact across these areas, we have employed a variety of methods including interviews with teachers, parents, other relevant service providers; informal reports such as communication logs and teacher notes; rating scales; natural documents such as school incident reports, report cards, medical records; and direct observation. The following assessment approaches are currently being used by the Consortium.

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Behavior Change

Constructive behavior change still serves as the foundation on which positive behavior support is evaluated. However, it is important to realize that there are times when an individual student's behavior does not immediately change, but their environment is positively altered by the support activities of the student's team. In other words, occasionally a child's behavior may remain the same, but the child's teachers and/or parents have learned methods to more efficiently deescalate crisis situations (e.g. the support team may be able to assist parents in community integration activities with their child despite problem behavior).

Alternative Skills After PBS			
	Frequency of Use	Appropriateness of Use	Independence of Use
More	392	394	361
No Change	28	---	49
Less	5	23	6

Efficiency of Support Strategies to Teach Alternative Skills via PBS				
	How Well It Worked	How Comfortable To Implement	How Consistent Was Implementation	How Much Interference With Routines
1. Not at All	6	2	1	208
2.	27	10	27	100
3. Somewhat	84	84	84	73
4.	175	108	135	33
5. A Great Deal	144	267	225	19

The Behavior Outcomes Survey assesses whether behavior problems occurred more or less often, were more or less severe, or occurred for longer or shorter duration following implementation of an individual support plan. Student acquisition and use of socially acceptable alternative skills are also assessed in terms of their frequency, appropriateness, and independence of use. In the context of assessing behavioral outcomes, intervention strategies are further evaluated by team members to determine whether the supportive strategies worked well, whether the team was comfortable with the strategies, whether the strategies were used consistently, and whether the strategies interfered with typical daily routines. We have found that these lines of inquiry help to cross reference responses with actual behavior change as measured through direct observation. Further, this information begins to delve into important issues of social validity, including evaluation of team members' feelings and perspectives about the effectiveness of interventions.

Problem Behavior After PBS			
	Occurrence	Severity	Duration
More/Longer	31	14	16
No Change	28	40	32
Less/Shorter	458	445	424

Efficiency of Support Strategies to Reduce Problem Behavior via PBS				
	How Well It Worked	How Comfortable To Implement	How Consistent Was Implementation	How Much Interference With Routines
1. Not At All	6	2	1	235
2.	33	11	33	109
3. Somewhat	94	94	94	77
4.	197	135	150	41
5. A Great Deal	170	296	253	20

The following depicts data generated through the Behavioral Outcomes Survey from in excess of five hundred team members from the Consortium's initial fifty student-centered teams.

Quality of Life Survey/Interview

This instrument has 22 items addressing various quality of life domains including: changes in the child's relationship with family and peers; changes in the child's participation in school and community activities; changes in the child's ability to express personal preferences; changes in the child's overall quality of life including general health and well-being; and satisfaction with supports provided to the child and team. Items are scored by team members using a Likert Type Scale of one through five (1 "much worse," 3 "somewhat better," 5 "much better").

Data from our initial fifty student-centered teams following application of PBS are depicted below. Data continues to be collected from newly established teams prospectively.

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Quality of Life Survey

Sample Items	Mean	Median
1. The child's relationships with family members (i.e., parents, siblings, etc.) are...	4.12	4
2. The relationships with peers the child has now are...	4.25	4
3. The child's participation in school and/or community activities of their choice is...	3.94	4
4. The child's ability to express personal preferences is...	3.64	4
5. The relationships the child has with members of the community (i.e., store clerks, neighbors, waitresses, etc.) are...	4.42	5
6. The child's relationship with teachers/school personnel is...	3.98	4
7. The child's access to activities that are personally stimulating is...	3.78	4
8. The child's self-confidence is...	3.79	4
9. As a result of PBS, I feel the child's quality of life is...	4.47	5
10. The child's general health and well being is...	3.96	4

Note: Total Respondents n = 517

Summary

The previously highlighted information represents a brief review of outreach efforts by the Consortium. While not comprehensive, this synopsis serves as an efficient description of the Consortium and its impact in the three state region. Of particular interest is the Consortium's endeavors that reflect emerging and expansive trends in evaluating the impact of support. Parties interested in obtaining additional information and materials are encouraged to check out the Consortium's Website at www.positiveapproaches.org .

Consumer Satisfaction Survey

The Satisfaction Survey assesses elements of support and team functioning. Open-ended questions in this instrument help to understand what team members liked most and least about the process. Consumer satisfaction is important in that often the initial focus of the Consortium's training/consultation has not exclusively focused on individual students. Rather, outreach has typically also prioritized facilitating changes in perspective and subsequent actions of team members, supportive relationships, and the team's ability to effectively and efficiently solve problems.

Data from the Consortium's initial fifty teams is depicted in the following table to illustrate the range of items asked and typical responses. A Likert Type Scale was also used in the Satisfaction Survey (i.e., 1-"strongly disagree" to 5-"strongly agree").

Consumer Satisfaction Survey

Sample Items	Mean	Median
1. The team is able to agree on strategies for the focus child.	4.35	4
2. The team works together to address the focus child's needs.	4.43	4
3. The team is able to collectively problem solve.	4.31	4
4. The agencies that agreed to work with the team to meet the focus child's needs continue to be involved.	4.10	4
5. The interactions between agencies, support providers, and family members is productive.	3.97	4
6. My vision for a positive future for this child has improved.	4.47	5
7. The number of environmental changes that support the child at school has increased.	4.50	5

Note: Total respondents n = 517

The Consortium anticipates further dissemination of information relevant to outreach with more in depth emphasis on evaluation of impact in a future TASH newsletter.

About the Authors

The authors of this report are collaborators in the Tri-State Consortium on Positive Behavior Support. Please address all inquiries to Dr. Tim Knoster at 570-523-1155 ext. 2213 or tknoster@csiu-pa.org

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ACCESSIBILITY AND ACCOMMODATIONS

You are responsible to make your own reservations for hotel accommodations. This information applies only to participation in the conference sessions and activities.

Sign Language Interpreter *Please indicate dates and times needed:* ______

Every effort will be made to accommodate requests for foreign language interpretation. Please specify language requested: ______

Please list any accessibility/ ADA accommodation needs: ______

Every effort will be made to accommodate requests for special dietary considerations. Please specify your dietary needs: ______

REGISTRATION COSTS (must be paid in U.S. Funds)

Registration Category		
☐ Individual Registrant	$ 249	
☐ Parent/Family Member	$ 149	
☐ Person with a disability	$ 149	1. Enter Cost Here ⇨ $ ______

Discounts:		
Earlybird Registrations — $20.00 (Must be sent with payment by May 3, 2000)	Subtract $20 per registrant for each discount	
TASH Member Discount — $20.00 Current TASH Member # ______	2. Subtract Discount Here ⇨	$ - ______

REGISTRATION FORM

After July 24th registration will be on-site only and a $25.00 on-site registration fee will be added. *Please register early.* We may not be able to accept on-sites if registration closes.

3. Add Late Fee Here *(if applicable)* ⇨ $__________

Enter Total Conference Registration Here (Total from 1-3 above) ⇨ $ __________

Pre-Conference Workshops 1:00–4:30 PM *(registration is in addition to the conference fees)* — Saturday, July 29th

1st Choice # ________ **2nd Choice: #** __________

PC-1. Implementing Individualized Funding: The Importance of Parent Leadership
PC-2. Asset Based Community Development
PC-3. Creating Your Own Microboard
PC-4. An Introduction to Creative Facilitation and the PATH Planning Process
PC-5. Developing an Individualized Budget

☐ TASH Member	$30.00
☐ Individual Registrant	$40.00
☐ Individual with a disability/Parent/ Family Member	$25.00

Enter Pre-Conference Fee Here ⇨ $ __________

TOTAL AMOUNT ENCLOSED: $ __________

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Questionnaire

To help us allocate space, please answer the questions below. The answers will give us an idea about what you hope to get from the conference sessions.

Answers

Please rate how important this topic area is to you by checking the box that indicates whether the information would be important for you.

	Very Important	Pretty Important	Important	Not too Important	Not Important
1. HOW TO DO IT: I want a broad range of practical information about how to promote and/or develop Self-Determination and Individualized Funding.	☐	☐	☐	☐	☐
2. NEWS FROM ELSEWHERE I want to find out about IF/SD initiatives in other states and countries.	☐	☐	☐	☐	☐
3. MANAGEMENT AND LEGAL ISSUES I want opportunities for in-depth discussion about technical and legal issues raised by the development of SD/IF.	☐	☐	☐	☐	☐
4. PERSONAL EXPERIENCES I want to hear from people about the effect that SD/IF programs have had on their own lives.	☐	☐	☐	☐	☐
5. THE BIG PICTURE I want a chance to think about and discuss how SD and IF fit into the wider global themes such as citizenship, social justice, community and consumerism	☐	☐	☐	☐	☐

Other Comments:

Acting on a Vision: Agency Conversion at KFI, Millinocket, Maine

Continued from page 24

> *The lessons of [KFI's] experience suggest that key components of this process include a value base that plays a strong role in guiding decisions and actions, persistence, creativity, a focus on relationships, and collaboration. All of these components, combined, have facilitated an organization transformation that now enables KFI to assist people not only with community presence, but to have meaningful community involvements and connections, which are keys to true community participation and membership.*

others with disabilities in the workshops. In the field of human services, sometimes this is used as part of the rationale to keep workshops and other facilities open. KFI staff felt that this was not a reason to keep the workshops open. However, they do feel that it is important to value and honor these relationships, and support people to maintain them through visits, calls, small gatherings, and so forth. At the same time, KFI staff feel it is equally important to assist people to have opportunities to get to know and spend time with community members that do not have disabilities.

Thus, a significant amount of staff time and energy is focused on thinking of strategies to promote diverse community connections and social networks. KFI staff themselves have forged positive relationships with many community groups, organizations, and individuals, and this serves as a positive link to the community for some of the people they support.

❖Relationships between staff. A strength of KFI is the emphasis that is placed on development of positive relationships between staff. As a result, staff seem to feel supported by and invested in the agency. Many have made long-term commitments to the agency, as well as to the people they support.

Overall, KFI has helped many of the people they support to develop diverse community connections and relationships. At the same time, as in many other agencies that give priority to this, some of the people they support are still relatively isolated socially. Thus, a challenge is the ongoing work of relationship-building and community-building.

Commitment to Continual Learning
The agency has continuously evolved in its learning about how best to support people in the community.

people in the community. For instance, initially, upon moving people out of the workshops, they used work crews and enclaves. However, they found these did not adequately match their vision of promoting true integration, and they began developing more individualized jobs and supports. In addition, staff did not consider the closure of all of the facilities as an endpoint, but rather as a turning point enabling them to focus all of their energy on ongoing learning about the people they support and how best to support them in community life.

Through its conversion, KFI aimed to move from services that promoted segregation or simply community presence, to services that assisted people to lead rich, meaningful lives in the community. Their experience illustrates that such organizational transformation is possible. The lessons of their experience suggest that key components of this process include a value base that plays a strong role in guiding decisions and actions, persistence, creativity, a focus on relationships, and collaboration. All of these components, combined, have facilitated an organization transformation that now enables KFI to assist people not only with community presence, but to have meaningful community involvements and connections, which are keys to true community participation and membership.

The preparation of this article was supported in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred. The Center on Human Policy subcontracts with TASH for space in this newsletter.

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The Kelso Debate: Viewpoints and Perspectives

Who will speak for Steven Kelso?

By Mary Johnson

The story broke into the national news the week between Christmas and New Year's. A rich Pennsylvania couple, Richard and Dawn Kelso, had been arrested and charged with child abandonment after dumping their 10-year-old, Steven, at the Wilmington, Delaware's Alfred I. du Pont Hospital for Children.

The Dec. 28 Philadelphia Inquirer reported only that Dawn Kelso had "wheeled her son into the Alfred I. du Pont Hospital for Children around 10:45 a.m. Sunday, then carried in several boxes filled with his possessions, left them in the lobby, and fled." The child was "multiply handicapped."
Dawn Kelso was being held at the Dolores J. Baylor Women's Correctional Institution in New Castle after failing to post $2,300 cash bail. Richard Kelso was being held at the Gander Hill Prison in Wilmington after failing to post $3,000 cash bail, reported the Inquirer.

Soon enough, news reports took on a different flavor. A spokesperson for Greater Philadelphia First, "a civic association of business chief executives from 33 of the region's larger corporations," called the Kelso affair "tragic."

"The only thing I can think of is that it is very difficult to care for a severely disabled child, and be the president and CEO of a major company," said the spokesperson.

Dawn Kelso, 45, had been appointed by Pennsylvania Gov. Tom Ridge in 1997 to serve on the 20-member Pennsylvania Developmental Disabilities Planning Council; her term expired a few days after she'd dumped her son at the hospital. Associated Press Writer Michael Rubinkam reported Council chairman Paul O'Hanlon as saying she'd "expressed frustration in dealing with agencies that sent nurses to her home to care for the boy."

The Ridgaway Philips home health agency told Rubinkam that it "provided nursing care for Steven for 10 hours a day." "And the Kelsos hired nurses for an additional eight to 10 hours a day," wrote Rubinkam.

They talked off the record. They recited stories they'd heard. The Kelsos dumped Steven at the Wilmington hospital every Christmas, they said. This year the hospital had said they didn't have room for him; the Kelsos pulled their stunt and dropped him anyway. Dawn Kelso was rich, said those who knew her as a member of the DD Council. She had little grasp of the problems average disabled people encountered with the system.

Rumor. Innuendo. No one would speak on the record. No one wanted their name associated with what they thought about Dawn Kelso.

"She had piles of services," one source told us. "This was a personal crisis between her and her husband — not a 'systems' issue."

"Your story should be about the danger of misdirected public debate."

Mary Johnson is the editor of Ragged Edge magazine.

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"I am constantly astonished that everybody wants to be seen as understanding and compassionate — toward the parents." *Dave Hingsburger*

By Dave Hingsburger

People offer incredibly positive hypotheses for why the Kelsos abandoned their 10-year-old son: lack of support, their own emotional state, their unpreparedness for their life with him as a son, the severity of the disability. In any other than the disability world, this would be viewed as blaming the victim.

On New Year's Day I tried a little experiment. I was out for brunch with a group of gay men (Brunch, for gay men, is a town hall meeting.) I knew that one of the men had been placed into a private psychiatric institution when he was 12 or 13 years old so that he could be cared for by professionals. The professionals would be able to fix him. He would learn to love differently.

I knew his story from years ago, and during brunch I brought it up. He, having a lot of distance from this now, took my opening and told the story himself, replete with descriptions of his incredible sense of abandonment and rejection by his parents, with whom he has never really reconciled.

After he was done I used the language I'd heard being used to excuse the Kelsos. I said, "Well, we need to understand where the parents were coming from. They might have been suffering from some kind of shock to the discovery that their son was gay. They might have felt that they couldn't be expected to raise him, that his care would be better done by professionals. . ."

I didn't get any further. There was an eruption at the table. People were furious that I would even suggest that abandonment was an appropriate response to the discovery that your child was gay. People shrieked — I'm not exaggerating — that a lot of street kids are abandoned gay kids, abandoned by parents who "couldn't cope."

Yes, I expected this reaction. What I was really interested in, while I was being chastised, was the look of absolute peace that came over the man whose story prompted this discussion. He was basking in the understanding and support of his friends, his community.

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The Kelso Debate: Viewpoints and Perspectives

Continued from page 32

How must it feel to be a 10-year-old abandoned by your parents?

But there's another question we need to ask ourselves: How must it feel to be abandoned by your community?

Dave Hingsburger is involved with the self-advocacy movement for people who have developmental disabilities. The author of 21 books, his writing appears regularly in disability rights magazines.

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The following viewpoints were shared via TASH's Update E-Mail Listserve, a new online discussion group. See page 12 of this newsletter for information on how to join.

By Bill Coffelt

I certainly have asked why I feel so strongly about this issue. It would certainly be easy to put it behind me and move on. I really don't desire to risk alienating so many whose respect, trust, and friendship I value so much. Obviously, when I accuse others of bringing their baggage and life experience to this issue, I am guilty of doing the same.

I still believe this is a family support, not disability issue. I believe it is about a ten year old child and his family. What happened to Steven happens to far too many kids, whether they have a disability or not. Or whether they were abandoned or not. When I placed Bill at Sonoma Developmental Center, it most likely did not feel any different to him than Steven's "abandonment" did to him. Most likely, it was worse for Bill because he got nowhere near the quality of care that Steven received.

Yet, no one accused us of abandoning Bill, because we made arrangements beforehand and remained involved. Don't you think I have thought a lot about how Bill felt when I walked out of the Oaks Unit that June morning ten years ago and left Bill behind? What have I done since? I have worked hard to be Bill's dad. I have worked hard to help prevent other families being in the same situation. I supported and worked for foster family options. I worked for legislation that would include "wrap-around" services as an option to help keep families together. I worked for legislation that helped families be involved in their child's life when the child was placed out-of-home, by trying to make the regional center develop options close by.

I imagine the grief of all parents who place their children out of home. I am tormented by what all children think who that happens to. Disabled or non-disabled.

The chances are greater that Steven will grow up to think like Mike and the *Electric Edge* thinks if this family doesn't receive the help it needs to be whole. If Steven doesn't get to grow up with his family. That most likely won't happen if people continue to reflect on what happened, rather than how to fix it. We need to be non-judgemental. We need to do whatever it takes. Those are the two basic principals of the wrap-around philosophy.

I feel the best way to prevent Steven from being a Mike or *Electric Edge* is to move away from the perspective of those who bring their life experience to the discussion and focus on solving the problem. Then maybe when Steven is an adult, his perspective will be different.

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By Dick Sobsey

Parenthood is a big responsibility. Raising any child requires a lot of time and a lot of money and a lot of other personal resources. Some kids require more than others and every child will require more than a parent feels that he or she has to give at some point.

Children do not always turn out to be what their parents want. Some kids turn out to be boys when their parents want girls. Some kids grow up to be homosexuals when their parents were hoping they would be heterosexual. Some grow up to be struggling artists when their parents were hoping that they would be stockbrokers or plastic surgeons. The children of staunch conservatives sometimes grow up to be liberals. Some kids have disabilities and need more care, even though their parents did not plan things that way.

Being a parent is not like purchasing a BMW. If you are dissatisfied, you cannot just park your kid back at the dealership.

As the parent of a child with a severe disability, I have great sympathy with the demands that parenting can put on parents. I even believe that sometimes it can be particularly tough to be a family that has lots of apparent resources because everyone assumes you can handle things.

But child abondonment is simply child abandonment and it is no different for parents of kids with disabilities.

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A TIME TO SPEAK OUT ON THE KELSO TRAGEDY

By Steven J. Taylor

When Dawn and Richard Kelso left their 10-year-old son, Steven, at a hospital the day after Christmas along with a note that they could not care for him anymore, they did something that is wrong, terribly wrong.

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The Kelso Debate: Viewpoints and Perspectives

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Any serious discussion of the Kelsos must begin with an acknowledgement that what they did is wrong. It is not sufficient to state, "I do not condone what they did, but. . .," quickly switching the subject to the shortage of home nurses or the inadequacy of home care supports for families of children with severe disabilities.

For the national media, the Kelsos' actions and the subsequent criminal investigation contained elements bound to capture the public's attention: a father who is the chief executive officer of a Fortune 500 company, a mother who was a respected advocate and member of the Pennsylvania Developmental Disabilities Planning Council, and a child who represents some people's worst nightmare -- a disabled child, a cerebral palsy child, a medically involved child, a burden. Although it is difficult to accept the claim that wealthy parents could not obtain adequate home care for their son, some parent advocates were eager to grant media interviews testifying to the hardships families face in keeping their sons and daughters with disabilities at home. Predictably, Polly Spare of Voice of the Retarded (VOR) put her own "spin" on the Kelso family tragedy: see, this is what happens when you close off the institutional option and push families to the "breaking point" by depriving them of "choice."

So Steven Kelso became the Elian Gonzalez of our field -- a symbol in which one group used him to present one position and another group used him to present another. Who would try to look at the situation from Steven's perspective?

In a recent series of articles in the *Ragged EDGE*, several writers reflected on what Steven, as a person with a disability, might be feeling. Like *Mouth*, the *Ragged EDGE* is a magazine that publishes articles that are often provocative and controversial. Articles in *Mouth* and *Ragged EDGE* force me to think, even when they create discomfort. *Mouth* and *Ragged EDGE* are in-your-face from a disability rights perspective. That is why I read them; that is why I respect them.

Responses to the *Ragged EDGE* articles -- ranging from condemnation of the editors of the *EDGE* and *Mouth* to amateur psychoanalysis of the leaders of the disability rights movement -- from some pro-inclusion parents would have shocked me had I not heard these reactions before. Internet listserves have been abuzz about the Kelso tragedy. For suggesting that Dawn and Richard Kelso might have committed a wrongful deed, people have been attacked on the Internet as being insensitive, judgmental, uncaring, out-of-touch, and cruel.

The Center on Human Policy has long supported the central role of families in the lives of their children. We are committed to families. Yet parents are not always right.

What the Kelsos did is wrong. All human beings are inherently valuable; all children are inherently valuable. No human being, no child should ever experience what Steven Kelso did.

It is not the Center on Human Policy's place to pass judgment on the moral character, or souls, of Dawn and Richard Kelso. We condemn the actions.

To condemn the actions is not to say that home care, in-home nursing, or personal assistance for either adults with disabilities or families is adequate. To the contrary, we know that services, supports, and accommodations are woefully inadequate in practically every state and community. This is why we believe that disability rights activists, family members, and their allies must work together for change.

We recognize that human beings, by their nature, are imperfect and they make mistakes, some of which have tragic consequences for other human beings. To those who make mistakes, we should try to be magnanimous, at least until we know all of the facts. But we must never be afraid to condemn actions that are indefensible.

What the Kelsos did is wrong.

Steven J. Taylor, Ph.D. is Director of the Center on Human Policy. His e-mail address is staylo01@mailbox.syr.edu. To obtain a copy of "A Statement in Support of Families and their Children", contact the National Resource Center on Supported Living and Choice, Center on Human Policy, 805 S. Crouse Ave., Syracuse University, Syracuse NY 13244-2280. The National Resource Center is supported by the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services, U.S. Department of Education through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred.

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Early Morning Musings on Freedom and Love

By Susan Yuan

Some thoughts on the Kelsos and the outrage that has followed—

This one has been too easy to cast in black and white — 20 hours a day of nursing care, their comfortable economic status — but we're missing so many of the nuances and grey areas of life when we generalize this anger between families and people with disabilities. Freud identified the most powerful motivators

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The Kelso Debate: Viewpoints and Perspectives

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as Work and Love; but I think in individualistic, American society, the most powerful, often warring forces are Freedom and Love.

Freedom was the most important of these for me as I was growing up. I terrified my parents by wandering off alone in the mountains or the desert for hours, starting from as young as three years old.

How little of this freedom is available to Andreas, my son with disabilities. Only twice in his life did he manage to escape our surveillance — once at night, when we found him, an hour later, in the backyard of a neighbor, communing with the rabbits in their cage, and once at a vacation cabin, when we found him in a corral we had visited that day, right under the feet of the horses, happy and unharmed. For him, we try to structure "choices," but he never has that simple unrestrained, unstructured spontaneity we so value in our lives. Now, as he is older, he seems to have reconciled himself to this. He is "safer" than when he was little — but I wonder how much of this is the loss of hope.

Parents who commit to loving and caring for their children with disabilities also give up this spontaneity. It has been very hard for Andreas' stepfather. He married very young the first time, going from his mother's house to his wife's. He committed to loving and raising his own children, and then, at the end of his marriage, had a brief interlude of the kind of freedom that comes from being responsible for no one but himself. Then he married us. I have told him over and over that if he wants me to do something adventurous with him, all he has to do is tell me ahead of time, and I will arrange for respite. But somehow, the very act of having to tell me ahead of time calls up for him all the resentment at the loss of spontaneity and freedom. I try to understand it and make arrangements on my own and then offer him the time — but it still is never the same as being able to just decide to pick up and go do something because the day is beautiful!

On the one hand, parents whose commitment doesn't win out in the balance between love and freedom are condemned for the hardness of their hearts; on the other hand, parents who continue to provide ongoing care once their children have become adults are blamed for stifling the freedom of their sons and daughters. In the course of Andreas' 27 years of life, he has been cared for by easily more than a thousand paid caregivers, at school, at home, in the community. He has been physically abused, that I found out about, 8 times. How many times where no signs showed? And how many instances of neglect that left no signs but boredom and loss of expectations and hope?

Still, statistically, among more than a thousand caregivers, that's not a bad record. Yet, if these things could happen when he was living at home, with parents who bathe him and see his body every day, and who understand his communication, what could happen if he lived away from us, among people who might care, but not that much?

Parents are not saints and heroes any more than people with disabilities. We are human beings trying to balance all those internal and external forces in our lives. Sometimes we manage it well; sometime we screw up badly, for ourselves and for those we should care about. At those times, of course we need to think first, and most, of the people who got hurt — but save a little compassion for the people who screwed up and in their hearts, have to know that. Let's be there for each other. We're all we've got.

Susan Yuan is a parent and chapter representative, TASH-New England.

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By Denise Gould

I've rarely heard something put so well (as Susan Yuan's Regarding Early Morning Musings on Freedom and Love). I am by nature a very biased, bigoted, judgmental woman. People are forever telling me how lucky David (who has many disabilities) is to be my son and nothing, absolutely nothing, could be further from the truth. He has tried -- and sometimes succeeded and sometimes not -- to teach me that we all have a right to who we are and the choices we make.

We live with the implications and results of those choices. It is not my place or anyone else's to presume to judge the choices or the right that came with making them. Life is a journey of living.

As Susan has so eloquently put it "...safe can simply be a result of losing hope (or maybe dreams and vision)." Too often instead of recognizing that we all need the support and understanding of those around us as we "live life," it is easier to judge. I can't tell you how grateful I am that David, whose very being is simply a miracle, has given me in the freedom I feel when I am not engaged in the business of judgment and bias.

By the way, I have a long way to go and a lot more lessons to learn, but I have every faith in my teacher. Thanks, Susan, for touching my heart.

TASH NEWSLETTER

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Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

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TASH Newsletter

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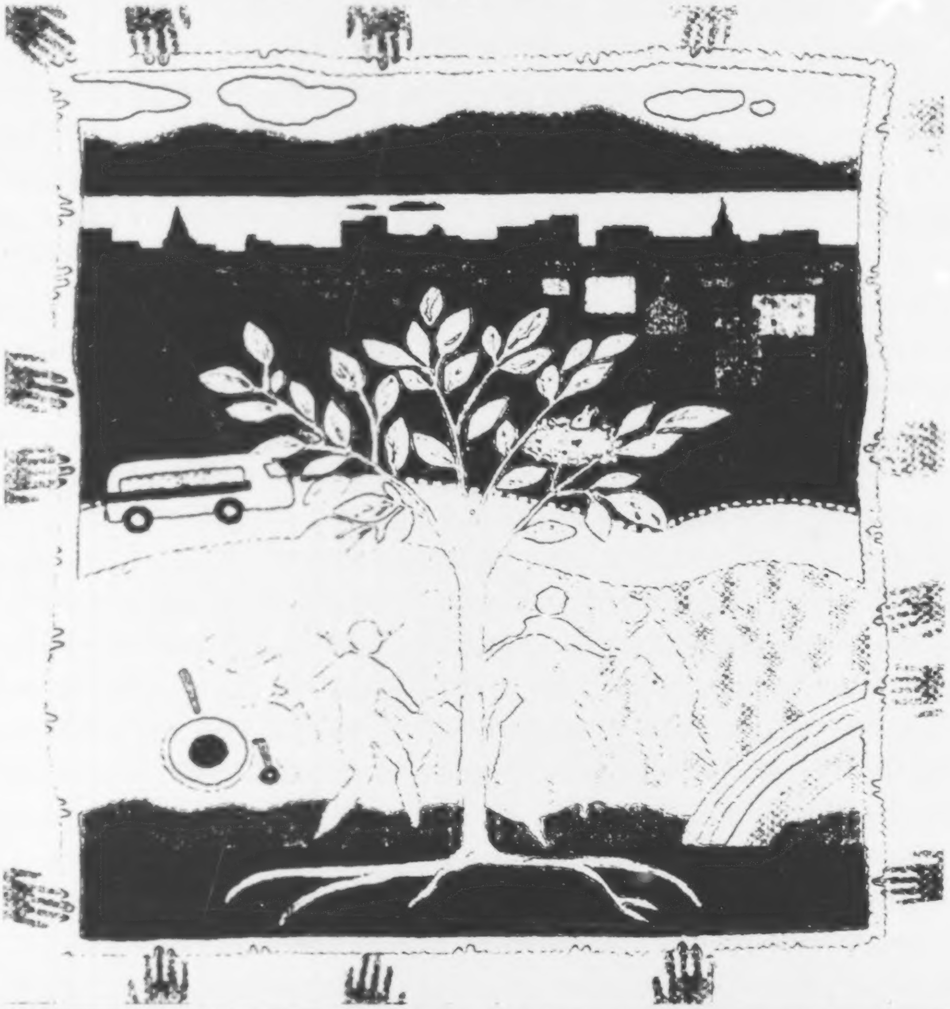
Embracing Sexuality



INSIDE: Sexuality and Teens with Developmental Disabilities, Thoughts About Sexual Orientation, Supporting Friendships, and Individuals with Significant Disabilities and Consent to Sexual Activity

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Supporting research and disseminating knowledge and information;

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Promoting inclusive education;

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Supporting progressive legislation and litigation; and,

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Promoting excellence in services.

Register NOW To Vote In November

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The National Mail Voter Registration Form is the one document that allows you to register to vote from anywhere in the United States. You can obtain the voter registration form from the Federal Elections Commission by going to http://www.fec.gov/votregis/vr.htm. You will need Adobe Acrobat Reader to view and print the forms. You may also obtain a copy by calling TASH at 410-828-8274 x104 or by sending an e-mail to <voterinfo@tash.org>

Each state has its own deadline for registering to vote. For more information and the registration deadline for your state go to: http://fecweb1.fec.gov/elections.html or call your state's board of elections.

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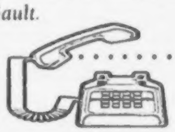

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2000 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
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- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
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Call for Papers

SEX

Get your attention? Of course. Sexuality and sexual expression are natural and important aspects of our everyday lives. Yet, for people labeled with severe disabilities opportunities for sexual expression are often overlooked, under supported, or outright denied. Moreover, people with significant support needs often fall victim to sexual assault and abuse. Sexuality and sexual expression are important concerns for all people, but until recently the topic has been given little attention for individuals who require the most support to express their sexual desires, communicate affection toward others, and enter into fulfilling intimate relationships with partners of their choice.

JASH, the journal of TASH, invites contributions to a special series on Issues in Support of Sexuality to be co-edited by Linda M. Bambara (Lehigh University) and Ellen Brantlinger (Indiana University-Bloomington). Specifically, JASH invites research studies (quantitative and qualitative), policy analyses, concept/position papers, reviews of the literature, and program or curriculum descriptions that address the following topics:

1. Barriers or impediments to the expression of sexuality and the development of intimate relationships (e.g., attitudes and behaviors of parents and caregivers; restrictive policies and practices of agencies; societal taboos and ethical/ moral dilemmas).
2. Analyses of legal, civil, and human rights issues surrounding the support of sexual expression and intimate relationships among individuals with disabilities (e.g., consent, fertility control).
3. Strategies or approaches for supporting sexual expression and intimacy among individuals with disabilities.
4. Curricula, program descriptions, and program evaluations that address sex education, safe sex, and personal safety (e.g., protection from abuse) for people with disabilities.
5. Reports of the incidence and prevalence of sexual abuse.

In addition, JASH seeks short personal reflection papers by parents, self-advocates, and other participants in the disability field for the Exchange section of the journal. Exchange manuscripts will be evaluated according to their contribution to the discussion of sexuality issues (see author guidelines).

Papers submitted to JASH for possible publication as part of the special series should be prepared according to the Journal's author guidelines, and all submissions will be peer reviewed. Within their cover letter, authors must indicate that they are submitting a manuscript to be considered for the special series on sexuality and indicate the type of manuscript they are submitting (i.e., research report, concept/position paper, review of the literature or program description, Exchange).

To submit a manuscript for consideration for this special section, send five (5) copies with a cover letter no later than **November 15, 2000** to:

Linda M. Bambara, JASH Editor, Lehigh University, College of Education, 111 Research Drive, Bethlehem, PA 18015.

From the Executive Director

BY NANCY WEISS

The National TASH Board is beginning a process of defining or re-defining TASH. Who are we? What is our mission and focus and/or what should our mission and focus be? The Board is asking for your help so that the opinions of as broad a range of members as possible is considered in their work on this issue.

We would appreciate if you would take a few minutes to answer the following questions. Your responses can be mailed back to me at Nancy Weiss, TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204; faxed to my attention at 410-828-6706; you can e-mail your responses to me at: nweiss@tash.org or you can respond to the survey via our website at www.tash.org (you'll find the survey on the website in a section titled "Member Survey").

Thank you for your input to this process!

— Nancy Weiss

TASH MEMBER SURVEY

How would you describe TASH to someone who had never heard of it before:

What type of organization is TASH?

What is TASH's focus? What should TASH's focus be?

Who joins TASH and why?

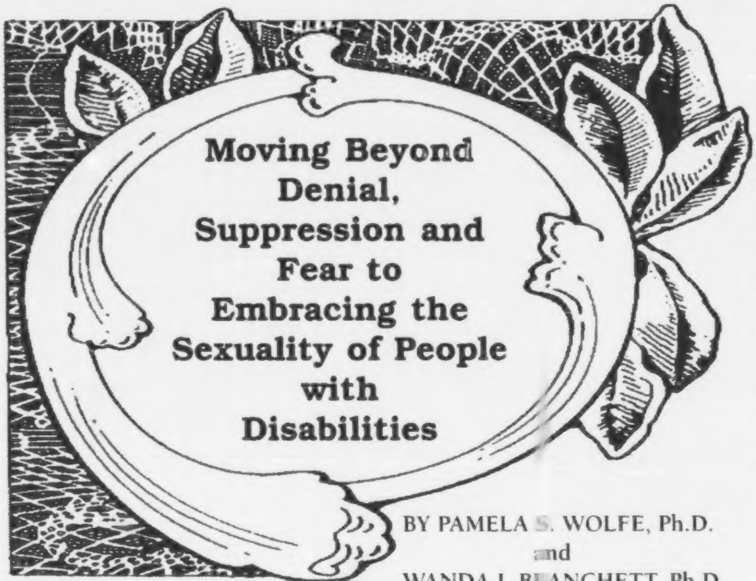
What makes TASH different from other disability organizations?

Why are you a member of TASH?

What additional input would you offer?

Your Name (optional):

____



Moving Beyond Denial, Suppression and Fear to Embracing the Sexuality of People with Disabilities

BY PAMELA S. WOLFE, Ph.D.
and
WANDA J. BLANCHETT, Ph.D.

Embracing our sexuality and expressing ourselves sexually, in the manner in which we choose, is a natural and fulfilling aspect of all of our lives. Thus, all of us are entitled to the right to sexual expression and access to complete and accurate information regarding human sexuality. As natural as sexuality and sexual expression are, few individuals with disabilities (especially those with significant disabilities) have been able to express their sexuality due to societal ignorance, fear, and denial of their sexuality and right to expression.

These attitudes are based, in part, upon historical events pertaining to issues of sexuality as they relate to individuals with disabilities. Throughout the 1800s and the early 1900s, individuals with disabilities were often viewed as asexual beings (Blanchett, Wolfe, & Ruhl, 2000). Consequently, their sexuality was denied altogether.

Individuals with disabilities were also sterilized during the late 19th and early 20th centuries, without their consent, to suppress their sexuality and rights to procreation (Elkins & Andersen, 1992; Lettrie & Fox, 1990). This era, known as the Eugenics Movement, supposedly emerged out of fear that individuals with disabilities, if allowed to procreate, were likely to produce offspring with disabilities, as well.

This inhumane treatment of individuals with disabilities resulted in a more aggressive and effective Disability Rights Movement that challenged our society to rethink its treatment of individuals with disabilities. The movement, lead by self-advocates, advocates, and human rights/policy organizations, was successful in ending involuntary sterilization and changing society's perceptions to some extent. Despite the progress that has been made, many individuals with disabilities still do not have access to socio-sexual information (Blanchett, 2000). This article will offer practical recommendations for providing socio-sexual training to students with disabilities.

Clear Policy Statements Should be Established by Districts and Agencies Regarding Sexual Information and Behavior

It has been argued that the present laws designed to protect individuals with disabilities may affect the legitimacy of sexual expression (Abramson, Parker, Weisberg, 1988). Agencies and school districts should have clear policies related to sexual behavior of those who utilize their services. However, such policies must acknowledge the basic sexual rights and responsibilities of persons with disabilities, not simply negate such activity. The development of policy statements should include a variety of constituents such as students, parents, community leaders, health care providers, educators, self-advocates, direct support staff and administrators. Policies should address the purpose and objectives of any sexuality training, a list of standards of policy and behavior, and how the policy will be implemented, interpreted and enforced.

Socio-sexual Information Must be Made Available to Students with Disabilities Beginning at a Young Age and Systematically Integrated into Individualized Education Plans (IEPs) and Transition Plans Throughout Their School Years.

Information related to sexuality often is not made available at all to individuals with disabilities at any age due to the misperception that they are perpetual children. However, age appropriate information should be made available to students as early as possible and be appropriate to their level of comprehension. For young children, concepts may be introduced such as the differentiation between public and private. In later years, that same concept could be expanded to include differentiation of appropriate places for sexual expression.

Further, socio-sexual planning should be conducted in a formalized manner during the development of transition plans when educators are preparing students to undertake adult roles and responsibilities. Socio-sexual issues can be addressed as a separate domain or may be infused into existing domains. For example, sex education goals can be infused into the leisure domain by preparing students for the development of relationships or in independent living domain areas by instructing students on the need to respect the privacy of others. Educators have the responsibility to

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plan explicitly for sex education and to assure that issues are addressed in a formal manner through inclusion on an Individualized Education Plan (IEP) or transition plan.

> A review of current sex education curricula reveals that content areas such as anatomy, birth control, and hygiene are typically addressed. However, curricula infrequently or inadequately address critical issues such as friendship, dating, respect toward a sexual partner, and non-heterosexual relationships. Granted, those of us who teach know that the area of social skills and friendships is often difficult to teach well. However, we also know that social skills and relationships are key to acceptance and quality of life and, therefore, must be addressed.

Socio-sexual Training Must be Taught by Knowledgeable Personnel who are Aware of their Personal Attitudes/Biases

The effect of personal values on educational content and delivery has long been an issue in educational programming. Service personnel have struggled with the question of whether content can ever be "value free." The issue of personal values becomes even more magnified when dealing with sexuality and persons with disabilities given that some individuals have severely restricted access to personal choice options. Research has indicated that educators hold different attitudes toward issues such as the right to have children, appropriate expressions of sexuality, and appropriate relationships. Further, these attitudes are often based on the level of disability of the individual (Wolfe, 1997).

Personnel delivering socio-sexual information should be aware of their personal values related to sexuality and persons with disabilities and actively guard against imposing their values on others. Equally, it is important to acknowledge that not everyone is capable or should deliver sex education curricula. Some personnel may not feel comfortable talking about sexual issues in a frank and open manner. Other individuals may only feel comfortable addressing individuals of a certain gender or sexual orientation. Personal traits associated with successful sex education include: credibility, knowledge, trust, "acceptingness," approachability, flexibility, and authenticity (Romaneck & Kuehl, 1992). Personnel who teach socio-sexual curricula should have access to accurate and current information. This information should be made available at both preservice and inservice levels.

Socio-sexual Curricula Should be Comprehensive in Nature

A review of current sex education curricula reveals that content areas such as anatomy, birth control, and hygiene are typically addressed. However, curricula infrequently or inadequately address critical issues such as friendship, dating, respect toward a sexual partner, and non-heterosexual relationships. Granted, those of us who have taught know that the area of social skills and friendships is often difficult to teach well. Equally, however, we know that social skills and relationships are key to acceptance and quality of life and, therefore, must be addressed.

Also frequently absent from traditional sex education curricula are strategies for consumer self-advocacy related to sexuality. Individuals with disabilities should be helped to develop the skills to advocate for their sexual expression so that they are not dependent on caregivers and other personnel. Self-advocacy in the area of sexuality might include the right to say no, protection from abuse, understanding sexual expression as a natural part of life, reduction of fear and myths, strategies for communicating choice, and how to speak out against discrimination.

Socio-sexual Curricula Should be Taught Using Best Practice Methodologies

The human service field has advanced considerably in our understanding of effective methods of instruction for persons with significant cognitive disabilities. Collective best practice for instruction includes technologies such as prior assessment of knowledge, explicit instruction, concept development such as the use of "big" ideas to group concepts, generalization and maintenance strategies, prompting, chaining, and reinforcement (Snell & Brown, 2000). These same technologies should be applied to teaching socio-sexual curricula in a systematic manner. If not outlined in the available curricula or materials, instructors should assess prior knowledge, present material using prompt systems with fading, make sure that there is adequate review of concepts, and that concepts are linked together in a meaningful way. Further, instructors should actively program for generalization of skills through strategies such as general case programming.

Our field has long struggled to maintain that persons with disabilities should have access to the same quality of life that is available to persons without disabilities. This right to a quality of life should extend to issues of sexuality, as well. Persons with disabilities should have the right to express their sexuality in the manner they choose. If our field is to move forward, we must accord individuals with disabilities with the right to sexual expression and the responsibilities that accompany that right.

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Silent AUCTION EVENT

Have you ever thought about the distinctive characteristics that make your state or country such a unique place in which to live? What about the eclectic culinary delights, one-of-a-kind gifts, sports memorabilia of your local teams and special sights and sounds that remind you of your favorite place? We would love for you to share those memories and experiences with others that may not have a chance to journey to your corner of the world.

TASH is introducing a Silent Auction as one of the featured highlights of the TASH 2000 Annual Conference in Miami Beach, Florida, December 6-9. We invite you to donate local items to be auctioned at the Friday evening event. Not only is the fair market value of all donations tax deductible, but proceeds from the auction will benefit the TASH Conference Scholarship Fund. The Fund is used to assist people with disabilities, parents and other family members to attend future TASH conferences.

If you would like to make a donation or find out more details, please contact Priscilla Newton, Director of Marketing, at 410-828-8274, ext. 102 or send an e-mail to pnewton@tash.org

TASH will acknowledge all silent auction donors in the official conference program, on TASH's web site and in the monthly Newsletter.

But I thought. . . Sexuality and Teens with Developmental Disabilities

BY DAVE HINGSBURGER, DEBRA SNELL VanNOORT and SUSAN TOUGH

"The police are here and they are saying awful things about my son. . ." "My daughter is pregnant, how can this be . . .?" "I thought my child would be safe from abuse — my God it was her teacher!" "I'm not up to this, my son has announced that he wants to get married."

The Sexuality Clinic at York Central Hospital in Richmond Hill, Ontario, Canada, has seen a rapid increase in referrals for teenagers who have made sexual mistakes. Many of these teens live in homes with their families, attend local schools and participate in community events. In 1981, the first year of service delivery, the Sexuality Clinic had a referral of only one teenager. This year, almost twenty years later, a full 25% of all clinic referrals are for teenagers with developmental disabilities.

As we design approaches for working with teenagers, clinic consultants, in the heat of frustration, often make the same clinical observation: "This is just stupid stuff." This comes from a realization that the behavior that led to the referral is often fairly typical for hormone-driven teenagers, but it also involves either bad judgement (on the part of the individual with a disability) or a panic-stricken reaction (on the part of school personnel or parents).

A number of these teens will be given a label that will have them considered "dangerous" for the rest of their lives when, in reality, they are simply making mistakes that are particular to a specific time of human development. We believe that it is possible to prevent some of these behaviors from occurring. The Sexuality Clinic is now actively promoting twelve recommendations for parents of pre-teens. A sidebar which contains additional information for parents of children with significant disabilities appears at the end of this article.

> *As children grow toward adulthood, parents must recognize that a child's increasing awareness of, and interest in sexuality is a normal developmental process. Your child doesn't need medication, surgery or punishment. Your child needs guidance.*

12 Recommendations for Parents of Pre-teen Children with Developmental Disabilities

1. Sexuality is an issue.
Many parents of children with developmental disabilities are poorly prepared for sexual interests developing in their children. One parent was told by her doctor that her child's sexual organ was just a "flap of flesh" that had no meaning for her child. Being told, or coming to believe, that one's son or daughter will be a "perpetual child" or is a "sexual innocent" is dangerous. By not seeing that a child is growing towards adulthood, parents may not feel moved to begin teaching boundaries. In fact, most of the Sexuality Clinic's referrals are "boundary violations" brought on by the impulse of a moment.

Parents need to realize that their child needs to be very aware of body changes, privacy rules, personal space and distance, relationships and permission. Most parents of typical children teach these rules and boundaries naturally through chance and circumstance as their child grows, but parents of a child with a disability may believe that it is OK (as occurred in one of our cases) to have their teenage child sit on the babysitter's lap when watching television at night. When that same child reached up and touched the babysitter's breast, everyone was shocked. Boundaries of body (private parts), of space (private places) and of topic (private subjects) need to be emphasized and adult forms of affection and closeness need to be developed.

2. Take a look at your child's social circle. Your child is getting older. So should his or her friends. Sometimes it's easy to slip up and think, "Well, his mental age is 5, so it's natural for him to play with little kids." Leaving your child, as a young teen approaching puberty, with a social circle of younger children is asking for trouble. The clinic has just supported a young family through an arduous court battle wherein their child was charged and found guilty of "sexually offending against a youngster." It seemed that the young man was simply "playing doctor," but unlike his typical peers who are engaging in exactly the same behaviors, his experimentation was with very young children.

It is not cruel to ensure that your child isn't socializing with kids much younger than him or herself — no matter how innocent it seems. Your child needs to socially advance and not be left in situations of danger. Ensure that others understand this, as well. Several years ago the Sexuality Clinic dealt with a

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situation where a young man in his late teens was in Sunday school with young children. He went into the bathroom to watch a little girl, with whom he'd been playing, use the toilet. She saw nothing wrong with this and told her parents in casual conversation about what had happened. Her parents did see something wrong with what the young man had done. The young man's parents had assumed that their child was in a class with other teens and were shocked to discover that the Sunday school teacher had decided that he should be placed with little children. The Sunday school teacher explained her decision by saying, "He's just a child in an adult's body."

3. Increase supervision by taking a look a little more often.
As soon as hair begins to develop on the body, it's time to become vigilant. When your child is socially engaged with others, take a look a little more often. Make sure that your child feels your presence and feels your supervision. Let him or her know that you can walk into a room where he or she may be entertaining a friend at any time. Don't say to yourself, "It's unfair to supervise her more during the teen years." Trust that parents of teens without developmental disabilities are doing exactly the same thing. And by the way, parents of kids without disabilities are worried about exactly the same consequences for sexual play.

One parent was so relieved that her daughter finally had a friend, that she let her daughter and a boy from her class go into her bedroom and would leave them for hours at a time. She had thought that her daughter, because of her disability, was asexual. The young male visitor, who didn't have a disability, did not make the same assumption. In talking to her afterwards, the mother said, "You know, I would have never let my other daughter have a boy in her bedroom at that age. I wonder why I thought that Shannon was different?"

4. Recognize that sexual development and curiosity is a normal process. Your child doesn't need medication, surgery or punishment. Your child needs guidance.
Every parent of every teenager has wished that his or her child's sex drive would run out of gas. Some doctors have advised parents to put their teenaged boys on sex drive reducing medications (or on a medication with sex drive reducing side effects) as a way of dealing with (or not dealing with) their child's burgeoning sexuality. Others have suggested sterilizing young women with disabilities as a way of getting around the "messiness" of menstruation. These ideas are old, tired and wrong, Your child is going through a normal developmental period. As hard as it may seem, he/she will get through it and grow into adulthood.

Living a "normal" life was a hard won battle for kids with disabilities. Your child will now begin a "normal" battle with you. They will have more than a sex drive. They will have a drive for relationships with others. They will have a drive for intimacy with another. They will want to establish themselves as separate from you. We have three bits of advice: Let Go. Let Learn. Let Live. That doesn't mean that you just let your child go through puberty and sexuality without guidance. They will need your input. If your eyes are set on guiding them to a fulfilling life full of relationships — you've set your sail correctly — and your guidance will be fair. If your eyes are set on a life without other relationships — your guidance will be interference.

5. Know when to be "askable."
Adolescent body changes are scary. Know when to intervene. When your child is beginning to get erections or is developing breasts, become "askable." For kids with disabilities, being "askable" might be slightly different than for parents of other teens. Your child may not have the language or the assertiveness necessary to ask these questions. You may need to see a teachable moment and set up the situation by actively inviting questions. "I've noticed that you like looking at pretty girls when we go for a drive, would you like to ask me any questions?" You can also develop your child's sexual self-esteem by affirming the pleasurable aspects of being an adult while setting up a discussion. Saying things like, "It feels nice when that good looking guy at the bank flirts with you, doesn't it? Do you want to talk about boys?" promotes discussion as well as shows that you are willing to talk about their sexuality in positive terms.

6. Allow adolescent dreams — marriage, house, babies.
There used to be "Impossible Dreams" for people with disabilities. These were primarily about relationships. Many doctors have told parents that their child will never grow up, get married, and/or have children. Parents of kids with disabilities have been advised to "grieve the loss of the normal child and come to accept the child with the disability." Many parents say that the hardest thing about having a child with a disability is the realization that they won't ever walk down the aisle or hold a grandchild. Well hold on. The world has really changed.

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Sexuality and Teens with Developmental Disabilities

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Many people with disabilities have formed relationships and have parented and done so successfully. When your child dreams out loud about his future, let him. When she talks about getting married or having children, let her. Let him or her point at a big house with a white picket fence and express his or her desire to live there.

Even if your child never does marry or have kids, the dream is still wonderful. It's an honor to share the dreams of your child. It's cruel to crush them. One mother, fearing that she'd set her child up for failure, kept telling her daughter that dreaming of marriage was inappropriate. (Inappropriate?) She ended up by alienating her daughter. No, her daughter didn't get married. No, her daughter doesn't have a boyfriend. The fact isn't relevant; what's relevant is that your child is letting you see into a corner of her heart. Some of us have had dreams that have guided us through our lives — getting what we dream for isn't as important as having the dream.

Some of you will hear of a dream for a life lived in a gay relationship. It may seem like the world is asking you to climb another mountain, but remember that people with developmental disabilities are a diverse community — and some of them are gay. These dreams are just as real and just as important to your child.

7. Tight jeans and plunging necklines
(Forgive the absolute honest representation of our culture in this example.) Who hasn't walked by a couple of teens looking at clothes in a mall and heard them say, "That's just way too retarded," and then burst into laughter. Kids judge each other, rightly or wrongly, on what they wear and how they present themselves to the world. Your kid may want to wear fashions that you find abhorrent. Your kid may want to get pierced or have a tattoo. Well, you have the right to set boundaries the same as any parent does. Your kid will just have trouble defying you. It's hard to run down to the mall and get your nose pierced if your dad has to drive you. Try to be open to how your child wants to express his or her tastes in clothes.

You may think your little boy with Down Syndrome looks cute in a tie. The other kids think he looks "goonie." By being aware of fashion and keeping your kid up to date with what they wear, you help to give your child a big step up in school. Remember, he or she is already getting teased for being different, adding to that doesn't help.

8. Create social situations by accepting other people with disabilities as potential partners.
Many parents who have fought long and hard for full inclusion, who have avoided any hint of segregation, who have lodged law suits in order to free their children, find adolescence a trauma. It is hard to see other kids who once willingly played with your child, move on. It is hard to see your child look out at typical peers and see themselves left behind. It is hard to see your child socially alone. One mother said, "I was desperate. She was just so lonely. One night, against my better judgement, I put her in the car and headed off to Special Olympics. I cried myself to sleep that night. She had such a good time. She seemed to really relax and have a good time. In one night she met two friends who she wants to call and visit."

The fight for inclusion should have meant the fight for options, all sorts of them. But somehow the "option" of hanging out with others who have disabilities became wrong. Your child needs to find people with whom he or she can find partners and begin to date. It is highly politically incorrect to suggest that we notice a fact. That fact is that when most (emphasis on most) people with intellectual disabilities get married, they marry another person with a similar disability. The fact is that People First and other self advocacy organizations are often places where people with disabilities first meet their future wives and husbands.

One of the biggest problems that some people with developmental disabilities have is that they are uncomfortable around others who have disabilities. How mentally unhealthy is that? Being uncomfortable around people who are "like" you is a massive self-esteem problem.

This isn't to say that people with disabilities should be segregated together. It's just to say that they shouldn't be forced apart, either. If your child is going to have a chance at a real relationship, she has to love herself first, then have the opportunity to love others. One dad reported, "I think I denied my son the opportunity to be with others who had disabilities and in that way I could keep him celibate. I knew, in my heart, that he wasn't going to date the teenaged girls down the street. It was an odd way of denying him sexuality, while pretending I was getting him what was rightfully his. And now he's grabbed his sister's breast and pats his mom on the butt and leers at her. I'm a man, I should have seen this coming."

9. Seek out education and educational materials.
There are great books and curricula for teaching your child about sexuality. Make sure it's up to date about issues regarding AIDS and other STDs (sexually transmitted diseases). Urge someone to teach a class, and get your kid into the class.

10. Support relationships when they happen.
When your son or daughter meets someone, greet him or her and get to know his or her family.

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Sexuality and Teens with Developmental Disabilities

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11. React calmly.
When you find a condom in your son's wallet, put it back.

12. You'll need the hanky.
When your daughter marries, cry -- joyously.

Susan Tough is director of York Behaviour Management Services in Richmond Hill, Ontario, Canada. York Behaviour works with people with developmental disabilities.

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Dave Hingsburger is in private practice and is a consultant to the Sexuality Clinic.

Questions or comments about This article may be addressed to Dave Hingsburger at <diversec@interlinx.qc.ca>

There's still time to register for the First International Self-Determination & Individualized Funding Conference in Seattle, Washington, July 29-31, 2000!

Contact the TASH Central Office today at 410-828-8274 to request a registration application or visit TASH's web site at <www.tash.org> for additional information. But hurry! Space is filling up fast!

Sexuality and Teens with Significant Disabilities

"Sexuality. Hmm. Well, my child requires total care, so I don't think that I need to worry about issues related to sexuality." Many parents of children with significant disabilities ignore the fact that their child is becoming an adult. With all the work that needs to be done to just care for their child, sexuality seems like a needless worry. While it may be true in most instances that the greater the disability, the less likely an individual will form a relationship that leads to sexual expression, even so there are two facts that parents need to keep in mind when raising a child with a significant disability.

FACT ONE: Parents need to realize that their child is at risk to be sexually victimized. In fact, the greater the disability, the greater the risk. Given that your child can't always use words to tell you that he or she has been hurt, you need to think about how to protect your child and how to equip your child to protect him/herself against abuse.

One fact about sex education is that it can be done with all people with disabilities, across the entire disability spectrum. Your child may not need to learn about sperm, eggs, and fallopian tubes, but they can learn two important concepts.

1. Boundaries. What is acceptable caring and touching and what is outside of that boundary.
2. "No." How to say "no" in a non-verbal but assertive way to touching that is beyond the ordinary or touching that makes your child uncomfortable.

These are very teachable skills to even those with significant disabilities. One tool you can use to assist with this is the Protocol for Personal Care, developed for use with individuals who have significant care needs. It is available for a very low cost by contacting Community Options at 250-380-6363. This may be one of the most important contacts you make.

FACT TWO: The drive and need for intimacy is greater than the drive and need for sex. Change the question from, "How does my child meet his or her sexual needs?" to "How do my child's intimacy needs get met?' We can work at ways that children can get their intimacy needs met. Remember, you need to develop ways that your child, when outside of the family or in care, gets his or her intimacy needs met by care providers. It is absolutely inappropriate that others use touch as the primary way of meeting your child's intimacy needs. There are so many ways of doing this that one only needs to be creative. Don't forget the option of a dog, a cat or a rabbit as a source of unrestrained and appropriate intimacy. One group home we know of has a Newfoundland dog as a pet and she is a source of much love, touch and comfort to individuals with significant disabilities who live in the home. Laura may just be a great big old dog to you, but seeing her lay down on the floor and curl around a young man with a disability is beautiful (noisy, because both snore so loud you have to turn up the volume on the television, but beautiful).

Dave Hingsburger

TASH AWARDS

IT'S TIME ONCE AGAIN TO SUBMIT TASH AWARD APPLICATIONS!

Each year at the annual conference, TASH confers a series of awards that recognize individuals, teams, organizations, or media which exemplify the spirit and mission of TASH. Submit your application (found on the following two pages) today!

- Who comes to mind when you think of someone who has made a positive difference in the lives of persons with significant disabilities over the past year?

- Have you recently seen an outstanding media piece that embodies the values of TASH?

- Do you know of a student enrolled in a doctoral program in education or a related field who demonstrates leadership, advocacy, and commitment to efforts of individuals with disabilities?

- Is there a team of people working together to improve the quality of life for a person(s) with disabilities?

This is your chance to honor such accomplishments with official recognition. Please take the time to submit an application. Awards will be conferred as part of the TASH Annual Conference to be held in Miami, December 6-9, 2000. Award applications will be accepted through August 31, 2000. **Please be sure to indicate for which award you are applying on the application, and submit all required documents or information requested for that award.**

2000 POSITIVE APPROACHES AWARD

This award is presented to the person whose contributions have served to advance non-aversive intervention with persons who display challenging behaviors; have demonstrated outstanding efforts leading to the understanding of challenging behavior; and whose actions have advanced the use of non-aversive interventions and progress in the use of positive behavioral supports.

2000 ALICE H. HAYDEN AWARD

This $500.00 cash award will be presented to a doctoral student enrolled in a program in education or a related field and who demonstrates potential for leadership in teaching, scholarship, and service on behalf of people with significant disabilities. The individual needs to have demonstrated a continuing desire in working in partnership with people with disabilities in accordance with TASH values.

2000 MEDIA AWARDS

This award honors presentations in either print or film, which best promote the inclusion of people with significant disabilities in all aspects of community life, and which have reached a national audience. Criteria for selection include: high quality, accuracy of information, meaningfulness of subject matter, potential for consciousness-raising, and promotion of quality of life for people with disabilities.

2000 COLLABORATION AWARD

TASH will recognize collaborative teams of persons with disabilities, family members, professionals, community members and/or peers, who are engaged in projects and advocacy efforts to ensure the implementation of TASH values in their local community, or in a way that has affected others at a local, state, regional, and/or national level. The work of the recipients of this award should serve as an inspiration for other community efforts, and demonstrate creativity in supporting an individual or individuals to realize the goals of self-empowerment and full community inclusion.

2000 THOMAS G. HARING AWARD FOR RESEARCH

This award is presented to promote research and scholarly activity in the field of significant disabilities. The award will be presented to the author(s) of a study of particular significance that was published in JASH within the two years prior to the annual conference. The study will have demonstrated scientific merit, and have made an important contribution to the disability field.

2000 TASH AWARD APPLICATION

- Applications due August 31, 2000

How to Apply:

(1) Complete this application form - front and back- as fully as possible.

(2) Attach a brief narrative discussing why the nomination is being made. Please see the other side of this form for a list of supporting information and materials that must be submitted for the particular award you choose below.

3) Please indicate for which award you are applying. **Check only one award.**

- ☐ Alice H. Hayden Award
- ☐ Collaboration Award
- ☐ Media Award
- ☐ Positive Approaches Award
- ☐ The Thomas G. Haring Award for Research

(4) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than August 31, 2000. Send to:

Awards Committee
TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204

Person or Team Being Nominated:

Name of the Individual:
____

Street Address:________________________

City:____________________________

State/Province:__________**Country:**__________

Zip/Postal Code:________________________

Daytime Telephone: (___)________________

Evening Telephone: (___)________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

Name of team members (more room on reverse side)
____

Street Address:________________________

City:____________________________

State/Province:__________**Country:**__________

Zip/Postal Code:________________________

Daytime Telephone: (___)________________

Evening Telephone: (___)________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

Person Making the Nomination:

Name:____

Relationship to the team/person: ________________________________

Street Address:______________________________**City:**______________

State/Province:________________**Country**______________ **Zip/Postal Code:**______________

Daytime Telephone: (___)______________________**Evening Telephone:**______________

FAX:(___)______________________**E-mail:**______________________

Please provide as much information as possible about the persons who are part of this team. Please use additional paper if necessary.

Name of Team Member: ______________________________

Organization (if applicable): ______________________________

Street Address: ______________________________

City: ______________________________

State/Province: ______________ **Country:** ____________

Zip/Postal Code: ______________________________

Daytime Telephone: (___) ______________________________

Evening Telephone: (___) ______________________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member: ______________________________

Organization (if applicable): ______________________________

Street Address: ______________________________

City: ______________________________

State/Province: ______________ **Country:** ____________

Zip/Postal Code: ______________________________

Daytime Telephone: (___) ______________________________

Evening Telephone: (___) ______________________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member: ______________________________

Organization (if applicable): ______________________________

Street Address: ______________________________

City: ______________________________

State/Province: ______________ **Country:** ____________

Zip/Postal Code: ______________________________

Daytime Telephone: (___) ______________________________

Evening Telephone: (___) ______________________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

MEDIA CONTACTS

Please provide on a separate sheet of paper, the names and addresses of local radio, television, or newspaper outlets that would be interested in covering the presentation of the award.

AWARD APPLICATION REQUIREMENTS

Collaboration Award:

1. Attach a narrative which describes: a) the goal of the team; b) the interaction of the team members; c) the roles of the individual himself/herself, the family, peers of the individual, and/or people who provide paid support; d) the outcome of the team's efforts; and e) a brief narrative about the individual or individuals who benefited from the collaboration.
2. Attach at least three (3) letters which support the nomination. These letters should present specific anecdotal information or data which conveys an accurate picture of how this collaborative effort met the criteria for the award.

Positive Approaches Award:

1. Attach a description of the nominee's background in the area of significant disabilities. Please include a resume/curriculum vitae if appropriate.
2. Attach evidence of contributions related to positive behavioral support.
3. Attach three (3) separate one page letters in support of the nomination.

Alice H. Hayden Award:

1. Attach a curriculum vitae outlining your history of:
   a) higher education (including major, minor, degree, date of completion); b) employment (including dates, duties, name of supervisor); c) research and publications.
2. Also attach 500-1000 word essay which describes:
   a) your current work on behalf of individuals with severe disabilities; b) your educational and professional objectives.
3. Attach at least three (3) letters which support the nomination. These letters should be from professors who are familiar with your qualifications. The letters should present specific data or anecdotal information which convey an accurate picture of your current achievements and potential for significant contributions to the field.

Media Award:

1. Please provide a brief description of the project, including the medium used (radio, television, newspaper, magazine):
2. If the nomination is in the film category, please indicate the length of the video in minutes.
3. Attach two copies of the nominee's work, or of the specific project being nominated. If the nomination is in the print category, the submission must be neat and legible. If the nomination is in the film category, two video copies (VHS 1/2") must accompany the nomination. The submitted work must be sufficient to demonstrate that the work meets or exceeds the criteria for the award.

Thomas G. Haring Award for Research:

1. To be eligible for the award, the authors' manuscript must have been published in JASH within the two year period prior to the conference. The senior author must agree to be present at the upcoming conference, and to present the contents of the paper as a conference session.
2. To make a nomination, submit a letter which references the article, and addresses the study's significance, scientific merit, and the importance of its contribution to the disability field.

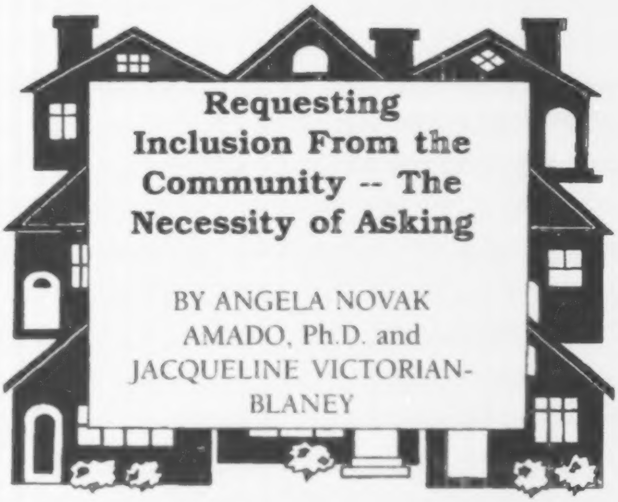
Permission to show video submittals:

If the nomination is in the film category, please complete and sign the following to hereby grant permission to TASH to show:

(Title) ______________________________________.

for, but not restricted to, promotion of the TASH Media Awards and the TASH Annual Conference. Similarly, as it applies to the promotion of the TASH Awards and the TASH Conference, the producers waive any monetary compensation .

Signature: ______________________________________



Requesting Inclusion From the Community -- The Necessity of Asking

BY ANGELA NOVAK AMADO, Ph.D. and JACQUELINE VICTORIAN-BLANEY

Working to support fully inclusive communities for people with developmental disabilities involves three groups of people: individuals with disabilities, staff of the human services agencies that support them, and community members. Most of the work to date about community-building, community connecting, and supporting friendships between individuals with disabilities and community members has been from the direction of staff supporting the individual to approach community. However, there is a different direction: asking community to include people with disabilities. Success for full inclusion involves the absolute necessity for "asking" and of becoming an "askee" (Schwartz, 1997).

John McKnight, Kathy Bartholomew-Lorimer and others at Northwestern University's Center for Urban Affairs and Policy Research were pioneers in this direction. In the original Logan Square Project in the City of Chicago (O'Connell, 1988), the neighborhood association was the organizing entity for efforts to determine to what degree ordinary citizens were aware of fellow neighbors and citizens with developmental disabilities, and for asking these ordinary citizens to involve and include all members of the community in their lives.

Currently, in the City of Seattle, the Department of Neighborhoods operates an inclusion project called "Involving ALL Neighbors," which is funded jointly between the City and the state Division of Developmental Disabilities to support each Seattle neighborhood in including its members with developmental disabilities. This is the only city in the country with a staff position dedicated to neighborhood inclusion of individuals with developmental disabilities. Various avenues for inclusion for individuals, their families and neighborhoods include: pursuing personal interests in the neighborhood, nurturing neighborhood hospitality, getting involved in existing neighborhood organizations, developing inclusive neighborhood organizations, and organizing neighborhood projects and efforts.

Another mechanism which some agencies have undertaken, which could be pursued by others without the framework of a formal project, is called Community Member Forums. In some small communities in southwest Minnesota starting in 1995, all the human services agencies in the area worked together to identify their vision for an inclusive community. Using O'Brien and O'Brien's "Framework for Accomplishment"(1991) and "Backward Planning," a poster with a graphic image of the group's vision was developed. The group of agency providers and staff knew that their vision would not be realized without the assistance, support and involvement of the community. The community needed to be asked if they had the same vision, how they saw their role in realizing this vision, and had to be asked to expand their current role. To get this feedback, a "Community Member Forum" was scheduled.

"We have always viewed the community as the web of relationships and belonging that people needed.... The concept of the community as an equal and active partner in achieving relationships and memberships for people with disabilities turned out to be just the shift in thinking that we needed to get unstuck."

Agency personnel invited people they knew in town who were key leaders in the community, people who were active and could make a contribution, and their own friends. Some of the people invited included agency board members, ministers and priests. This first group said they shared the vision and that the people who really needed to hear it weren't at the meeting. So additional Forums were scheduled.

In the second meeting, an auto dealer started speaking about his friendship with a blind musician. These two were both members of an organization called Ducks Unlimited (duck hunters who also work to preserve wetlands and marshlands). The blind musician had gone to the auto dealer to ask him to go fishing together. The auto dealer had accepted, they'd gone fishing several times, and had become friends. The auto dealer underlined the necessity of asking. He said, "I would never have gone to him to ask him. But just because I wouldn't have gone to ask him doesn't mean I'm not friendly or not willing. I had to be asked."

A minister in Nebraska who had been approached by a group home asking about potential friends for their residents also emphasized this necessity of asking: "I would bet a month's preacher's salary (not that that's much money) that every congregation in the country, whether it's Protestant, Catholic, Jewish or Muslim, has at least one person who is willing to

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Requesting Inclusion from the Community -- The Necessity of Asking

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develop a friendship with a person with a disability. But I would also bet a month's salary that 90% of them don't know that they have this willingness ... because they haven't had the opportunity to find that out, they haven't been asked."

In 1996 the southwest Minnesota Community Members Forum group committed to meet monthly for a year in the town of Fairmont. Some of the community members who attended included a local newspaper journalist, a county commissioner, a city council member, a man who had a radio show and a local cable access show, some high school students who were involved in a diversity initiative, an ex-social worker who had many connections in town, ministers, and a member of the Minnesota Valley Action Council. Some of the associations which became involved in the effort over that year included Knights of Columbus, Kiwanis, Women of Today, the Social Concerns Committee of a catholic church, and several ministerial associations in the region.

The Fairmont Community Member Forum group that met in January 1996, upon deciding to meet monthly for a year, felt they needed to have a goal or a mission — what were they going to accomplish? The community members asked how many people with developmental disabilities lived in this town of 11,000 people. The agency staff estimated around 250 adults. The group committed that by the end of the year, all 250 people would be connected with nondisabled friends, be part of clubs and groups, volunteer in ways that expressed their interests, and/or have ordinary jobs.

The community members saw it was entirely possible within a year to accomplish that for all 250 people! By the end of the year, progress was definitely more significant because of the Forum's involvement, however, not everyone was successfully connected by year's end. Agencies often had to re-organize their staff time, individual schedules, and agency focus. When asked why the group hadn't accomplished its goal, the radio host replied: "Because the agencies wouldn't give it up!"

MORE STUFF INSIDE

Discussion of the Minnesota experiences was shared in Louisiana, and a provider agency in Baton Rouge decided to also try these forums. Their experiences are shared by the agency director:

"After many years of commitment to person-centered supports for 26 people with developmental disabilities, our agency took a systematic and critical look at how effective we were being in helping people to achieve their personal outcomes. We were surprised and disappointed by how limited our assistance had been in supporting relationship and membership outcomes. We could point to some positive examples, but most people continued to live without friendship or belonging.

Another pattern was clear. Agency staff had developed genuine and reciprocal relationships with the people they were helping to support, often including them in family visits and events. Though these relationships had real quality, the person's circle of friends remained narrow and was significantly affected by the patterns of staff turnover and discontinuity that plague the human service world.

About the time we heard about the Community Member Forums in Minnesota, we had done all we could think of to do as a human service organization. The concept of the community as an equal and active partner in achieving relationship and membership turned out to be just the shift in thinking that we needed to get unstuck. We had always viewed the community as the web of relationships and belonging that people needed above all. But we had never seen the community as experts in building community. Despite our gloomy record on community-building, we still implicitly saw ourselves as the experts.

The strategy that represented the key breakthrough was the concept of the Community Forum. We adapted it slightly in that we began with the 26 people our agency served, rather than with a particular geographic community. But the major design was the same. Utilizing the community contacts or our staff, we identified and invited community leaders who lived in the same communities as the people we supported to attend a Community Forum. The community leaders at the first Forum included the president of the Elks club, a realtor, the director of a community center, a legislative aide, the owner of a fast food restaurant and the coordinator of a youth group.

We held the Forum at the home of a staff member, with plenty of food and refreshments. The agency director introduced the purpose of the Forum as seeking the advice and assistance of community leaders in supporting the people with disabilities at the Forum in achieving their particular dreams of membership and relationship. She acknowledged that human service agencies alone were incapable of achieving lasting and deep relationship and membership opportunities. She affirmed the community leaders in the room as the experts in community-building. In fact, as she pointed out, they were building community all the time.

Next, six people we support introduced themselves and described their interests. The community leaders insightfully brainstormed opportunities, some under their direct influence, others that they were willing to facilitate.

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Requesting Inclusion from the Community -- The Necessity of Asking

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One woman was interested in joining the Elks Club, a social club and service organization. With the help of the director, she was initiated three months later and is a devoted member.

The owner of the fast food chain hired one young woman. He has since spoken at a major conference regarding all she has brought to his business, making his store a better work community.

One young man with artistic gifts was invited to paint a mural at the community center. He did a beautiful job, and is now taking an advanced art course at the local university, where he is making some good ties with other students.

Another woman was assisted by a legislative aide to tell her life story to children at local schools. The aide also introduced her to two older adults at a nursing home to whom she taught signing and with whom she developed a real friendship.

We continue to hold Forums about every six weeks with new and former community leaders and both new and former people served by our agency. The same patterns of success continue: jobs, membership, and friendship opportunities. The community brings us not only their community-building experience and expertise, but the deeply-lived conviction that there is a place to really belong for everybody."

For further information contact Angela Novak Amado or Jacqueline Victorian Blaney, Human Services Research and Development Center, 1195 Juno Avenue, St. Paul, MN 55116.

REFERENCES

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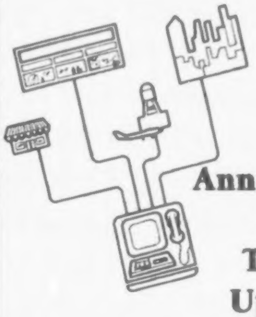

Announcing the TASH Update E-mail Listserve!

This is a forum for TASH members, friends and supporters to discuss the latest issues affecting people with disabilities. The listserve provides members and other interested persons with an opportunity to identify and connect with others who share particular interests, expertise and experiences.

You can subscribe directly from TASH's web site at www.tash.org, or you can send an e-mail to: <TASHUpdate-subscribe@egroups.com>

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

East Bay Innovations

440 Grand Avenue, Suite 425
Oakland, CA 94610

DIRECTOR - Employment Services

Progressive Oakland non-profit seeks Director of Supported Employment in Alameda County.

Requires experience with job development/training, support strategies, employee supervision, program budgeting, BA and 5 years experience. Salary: $35-$38K/yr., benefits.

Teachers Needed Mendham Township (N.J.) Schools

YOU may be the teachers (2) we need for our inclusion teams. Will co-teach with regular education staff. Knowledge of Spectrum Disorder and Down Syndrome essential. Send resume to:

Kathleen Woodward
Director of Special Services
Mendham Township Schools
West Main Street
Brookside, New Jersey 07926
EOE

Washington Elementary School District Phoenix, Arizona

Innovative program in large elementary district seeks special education teachers, speech pathologist, and occupational therapist for students with autism in Phoenix, Arizona.

Training provided in North Carolina by TEACCH. Special education teachers needed in all areas for ages 3-14. Arizona special education certification required.

Contact Carol Roth, Administrator for Special Services, Washington Elementary School District, 8610 N. 19th Avenue, Phoenix, Arizona 85021, Phone: 602-347-2632

School-linked Services, Part II

Opportunity Through Local Partnerships

BY WAYNE SAILOR

[This is part two of a two part article. Part I appeared in the April 2000 TASH Newsletter.]

In Part I of this two-part series, I discussed some of the implications of the rapid shift in federal and state welfare policies as we move into the age of globalization. As I write this piece, violent demonstrations are occurring in Washington D.C., led by the Mobilization for Global Justice against the International Monetary Fund and the World Bank. These demonstrations, deliberately organized by the AFL-CIO to call attention to the worldwide plight of workers under globalization policy, move into civil disobedience tactics as a way to capture media attention.

The Washington demonstration exactly mirrors the earlier violent demonstrations in Seattle against the World Trade Organization. Tactics of civil disobedience mainly on college campuses in the late 60's and early 70's were successful in forcing an end to the war in Vietnam, but during that period the mass media brought the excesses of the war with stark images to virtually all Americans on a daily basis. Not everyone agreed with the protesters, but everyone understood the basis for the protests. Today's protests are poorly understood. The media cover the sensational aspects of demonstrations, but apart from National Public Radio, provide few reasoned analyses of the underlying issues.

For people with disabilities, their friends and supporters, the issues loom large. As the federal and state governments implement new policies dismantling the welfare state, both crisis and opportunity became emergent at the local level. Some see only gloom and doom resulting from the multinational corporate network agenda. There is another possible scenario, however, with perhaps more of a silver lining. As federal and state governments further devolve resources and responsibilities to more localized systems through privatization and initiatives to create local agency consortium arrangements, such as those enacted by the California Healthy Start program and the Kentucky Education Reform Act, greater opportunity arises for direct consumer participation in structuring these new schemes for organizing supports and services.

In this article, one such localized arrangement, called "school-linked services," is examined. In the previous era, the age of industrialization, the welfare state evolved by creating systems of care. Well intentioned, these systems were grounded in a philosophy of protection under a doctrine of "separate but equal." People with disabilities, it was thought, needed to be cared for by highly trained professional specialists and in places where their basic human needs could be met in a manner that would be both economically feasible and convenient for service providers. Hence, we evolved special education and its separate placements, sheltered workshops, day activity programs and larger, more diversified, state institutions. Now we are at the end of the industrial period and systems of care suffer from two deficiencies. First, they have become expensive and the quality of care they provide has come into question. Secondly, the "consumers" of these systems have consistently argued for inclusion in the mainstream rather than to be "separate but equal."

Systems of care are now being replaced by what might be termed, perhaps optimistically, systems of opportunity. As tax-based resources targeted for special-needs populations become directed to more localized arrangements, the probability that the voice of participants will enter the conversation increases. At the turn of the last century, problems affecting specific groups of people were addressed at the level of the community and, in fact, it was these very processes that defined "community". America's sense of community was lost during the industrial age but it may, ironically, be poised to reinvent it in the age of globalization.

The premise of school-linked services is this: Why not take the special resources, services and supports available at schools (special education, vocational education, Title I, etc.), integrate them within the schools so that all resources are deployed to help all kids, and then link them, through a community planning mechanism, to similarly integrated community-based resources and supports (DD system, vocational rehabilitation, mental health, child welfare, United Way)? The result would be a "seamless web" of supports, resources and services that could be decategorized and planfully addressed to the needs of children, adults and families as articulated and chosen by the consumers.

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Reinventing Community in the Age of Globalization

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School-linked services (or "service integration") arrangements have been around since about 1972. They have not proliferated because efforts to integrate services and supports for special needs populations at the local level have failed to achieve an alignment with big-agency dominated policies and control of fiscal resources at the state and federal levels. The premise of school-linked services is this: Why not take the special resources, services and supports available at schools (special education, vocational education, Title I, etc.), integrate them within the schools so that all resources are deployed to help all kids, and then link them, through a community planning mechanism, to similarly integrated community-based resources and supports (DD system, voc rehab., mental health, child welfare, United Way, etc.)? The result would be a "seamless web" of supports, resources and services that could be decategorized and planfully addressed to the needs of children, adults and families as articulated and chosen by the consumers. Ideally these integrated, decategorized resources could then be co-located, either at schools or nearby so that everything from immunizations to food stamps and wheelchair adjustments could be obtained in a single "one-stop shop".

Until recently, model demonstrations of school-linked service arrangements have not proliferated by "going to scale" within communities or states. Recently, however, publication of impressive outcomes on health, social and academic achievement from some of the statewide initiatives, particularly Vermont, Kentucky and California, have begun to shift the momentum toward reinvestment in school-linked services initiatives.

The most common types of large-scale applications of school-linked services can be found in three arrangements: "school-based services"; "school-linked services"; and "family-resource centers." In the case of school-based examples, largely publicized through the writings of New York author Joy Dryfoos, high school campuses become co-location centers for integrated community services. Often health clinics, established on high school campuses, become the starting point for introducing social welfare programs, mental health and DD programs, job force development programs, etc., all at the school site. While there have been many successful outcomes from examples of school-based, service integration efforts, they have run up against significant resistance from religious groups concerned with abortion issues and "family rights." They have also been criticized for failing to achieve integration within schools with community services, for example, becoming clustered at one end of the campus and the rest of the school at the other end under a different administrative officer.

Where school-based systems have tended to focus on the high-school population, school-linked services arrangements have tended to be focused on the early childhood and elementary age groups. These arrangements are often associated with partnership agreements between school districts and one or more entities that have successfully integrated community supports and services through a single agency or a new, not-for-profit corporation, organized for that purpose. Models of this type will have some kind of planning board or council, usually with some consumer representation. California's Healthy Start initiative, now in its eighth year, uses this kind of approach and requires that the Local Planning Councils administering the programs have at least 50% consumer membership. School-linked services arrangements have struggled with efforts to create sustained funding for their consortium arrangements and have fallen prey to political changes in state-level administration. Colorado and Kansas both had school-linked services arrangements as state initiatives, but both melted down when a different political party captured the state elections. Many school-linked services arrangements have "facilitators" who are placed at schools to link families with service and support needs through the community consortium. A number of school-linked services arrangements have reported successful outcomes with disadvantaged populations, including those reflecting positive consumer satisfaction results.

The third model, family resource centers, tends to be almost exclusively identified with social welfare programs and often has few or weak ties to the schools. Where these programs do form partnerships with schools, they became very much like school-linked services arrangements but without the school site facilitators.

Recently, Hal Lawson, Katherine Briar-Lawson and others have written on the critical importance of inclusion and of incorporating special education resources into what they call "community schools." The community school movement is a formal partnership of schools, families of the kids, who attend the schools, and networks of community services providers, to not only integrate services and supports but to re-invent the whole community support agenda as part of the process. In the view of the Lawsons, special education and its students are regarded as resources to the school and to the community rather than populations in need of separate care. Inclusion is advanced as a way, not only for general education students to benefit from association with diverse kids, but to obtain special education resources that are needed for all students (ie., school-wide positive behavioral support; or school-to-work transition planning).

School-linked services arrangements such as represented by the "community schools" partnerships are helping to bring about the changeover from systems of care to systems of opportunity. When students and others with disabilities come to be valued for not only what they can accomplish despite adverse circumstances, but what resources they bring to the common table, then new choices and

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Reinventing Community in the Age of Globalization

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opportunities for full participation in mainstream society become possible. TASH members, with their immersion in a variety of service systems, and their wide exposure to interdisciplinary programs and professions, are well positioned to become involved with these localized adventures in systems change, and perhaps to strongly influence the course of their development.

In St. Louis and elsewhere, families of students with significant disabilities are talking about exercising the "buyout option." Bolstered by a recent federal court decision, this option allows schools and post-school support systems to come together to re-direct IDEA funds after the age of high-school graduation to job training, employment support and community living. In the south side of Chicago, Lou Brown, Sharon Freagon and their colleagues are extending special education transition and job support innovations to all kids, in high schools where the post-school unemployment statistics are as high for regular as for special education kids. Finally, in Kansas City and elsewhere, school-linked services arrangements are helping colleges and universities, through student participation in interprofessional training arrangements, to redefine the curricula and field experience requirements for human services professionals, to begin to prepare a professional workforce for systems of opportunity, rather than systems of care.

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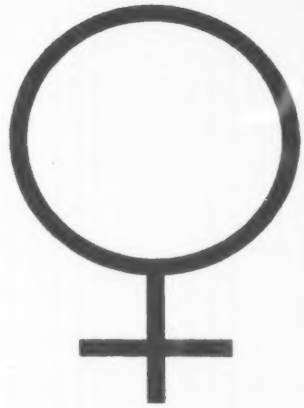
A DREAM IS REALIZED

The World Congress & Exposition on Disabilities (WCD), a precedent-setting international conference and trade show three years in the making, will take place at the Georgia International Convention Center in Atlanta, November 10-12, 2000. The WCD is intended to educate, inform and provide a useful exchange of ideas for people with disabilities and special healthcare needs and those involved in their care and development. Opinion leaders in medicine, education, research, technology and product development will gather along with caregivers and families for an intensive learning experience focused on the needs of all people with disabilities.

Seminars on three tracks (Track 1 is designed for physicians, OTs, PTs, SLPs; Track 2 is for the education community; and Track 3 is designed for direct support professionals, families, caregivers and people with disabilities) are being planned to best serve the show's expected 8-10,000 attendees. The entire curriculum has been developed by a Steering Committee made up of leaders in medicine, science, the government, the private sector, non-profit organizations and associations, educators and families, and is being produced under the auspices of the EP Foundation for Education, Inc., a 501(c)(3) non-profit organization.

In addition to the conference program, the event will provide an opportunity to examine the latest products and services from hundreds of exhibitors. The conference will also feature a career fair, as well as a number of Activity Centers, designed as interactive, educational and fun.

MARK YOUR CALENDAR NOW FOR NOVEMBER 10-12, 2000. FOR COMPLETE INFORMATION, VISIT WWW.WCDEXPO.COM OR CALL 877-923-3976.



People are People

BY JAMES MEADOURS AND
BONNIE SHOULTZ

James Meadours and Bonnie Shoultz first met in 1993, at an international self-advocacy conference in Toronto, Canada. Bonnie was a national advisor for Self Advocates Becoming Empowered (SABE) and lived in Syracuse, and James was president of Oklahoma People First. The next year, they met again in Alexandria, Virginia, at a national conference where James was elected as treasurer of SABE. They became friends, and have had much contact, through many meetings, conferences, and phone calls, ever since.

James is now Self Advocacy Coordinator for the State of Louisiana and is based in Baton Rouge. In 1996, he was elected Co-Chairperson of Self Advocates Becoming Empowered and is now Chairperson, assuming that position late in 1999 after Tia Nelis stepped down to devote more of her time to People First of Illinois.

Following are personal perspectives from James and Bonnie about sexual orientation and relationships between people who are gay and people who are straight.

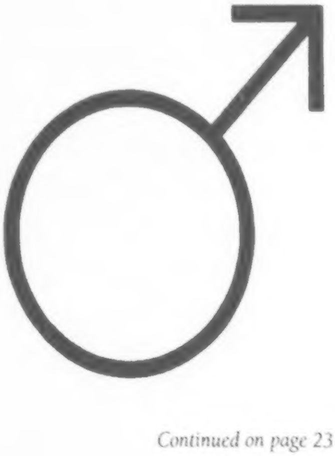
James: I am fairly young (33) and grew up in a conservative family. I did not know about people who are gay. I just assumed that everyone was the same. I am not gay myself, and I have had several girlfriends. After I got involved with People First, one of my friends told me she was gay. She had always been real supportive of me in my personal and professional life. It took a lot for her to trust me enough to tell me. I was not shocked. I didn't understand at first what being gay meant, but I started asking questions. I tried to figure out why she told me. She said it was because People First was "making waves" on the disability rights front and she was afraid that we would get attacked through her. She didn't want us to be shocked if we found out she was gay, so she told me and my brother about herself.

Later on, I used to worry about her. I was worried that people might hurt her or attack her. I told Bonnie about my worries, and she told me to tell my friend how I felt. A couple of weeks later, I did. She said I didn't have to be worried about her. She said, "I am okay," and that reassured me. At the same time, I got to know other gay people. They didn't know I knew they were gay, but I figured it out. I remember one time when one couple and I were getting ready to go out to eat, and I said, "I just want you guys to know that I support you and love you guys." They were really touched, and they told me later that they still talk about that and it makes them feel good.

I am not sure when I learned that Bonnie was gay. I think it was at my first SABE meeting. SABE had been meeting for about 2 1/2 years by then but it was my first meeting. SABE and People First of Connecticut were putting on a regional conference together, and it was about relationships. Bonnie and another advisor and a People First of Connecticut member did a workshop about being gay. One of the SABE board members got upset when he found out they were gay. He told me, "We should kick them out as advisors because they are gay." I told him, "They are our friends and they support us, and as a national organization we should be welcoming to all people. People are prejudiced against us and we know how that feels. So why would you want to do that to them?" Some of the other board members told him the same thing. Most of us felt like he didn't understand, that he was prejudiced because of ignorance, not because he was a bad person. He must have thought about what we said, because he became friends with both of them.

As I got more involved in self-advocacy in Oklahoma, I became more sensitive about this issue, and saw how people are ignorant and prejudiced toward people who are gay. Once there was a panel on the ADA, and it included people with different disabilities, and one was a gay man with HIV/AIDS. After the panel was over, people ignored him. I was the only one who shook his hand and talked to him.

In 1995 I became a VISTA volunteer for Oklahoma People First. In that job, I also saw the way gay people are treated, and how ignorant and prejudiced people can be. One time someone (not a self-advocate) said, "I will never see another Tom Hanks movie again," because he played a person who was gay and had HIV/AIDS. I said to her, "Why are you so accepting of me, as a person with a disability? Why are you so prejudiced against people who are gay and have AIDS?" She said, "Because you were born that way." I said, "I have friends who are gay and I don't appreciate that." She asked me who they were and I said I wouldn't tell her because people like her might hurt them. Then she got quiet and left.



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People are People

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I started going to the Catholic church when I was 11 years old. My dad's family was Catholic. In Tulsa, the Catholic church became really important to me. I met some really good friends there, and I did a lot with the church. But I started questioning my parish's attitude about homosexuality. I heard on the news that Disney was offering insurance and other benefits to same-sex partners. Our diocese was debating whether or not the church should sell its stock in Disney, and that really disturbed me because the church had always said, "Love one another as yourself," and I felt they should practice what they preach. It seemed hypocritical. The members of my church were talking about people who were gay or have AIDS. I was afraid to speak up. I thought they might condemn me. I had one friend in the church that I could talk to about that issue. I would talk to her a lot about it, and she would listen. I was testing the waters to see who I could turn to and I picked her. I found out I could trust her, and I talked more about it.

When I moved to New Orleans in 1997, I decided not to go to the Catholic church. The attitude of the members of my former parish really hurt me, and I couldn't get over my feelings about it. I didn't go to any church for almost two years. A while later, I moved to Baton Rouge but kept the same job. I was talking to Bonnie at the TASH conference in Seattle. I told her I was really at a crossroads regarding religion, and she told me she was concerned because she knew how much it had meant to me to be in a church. I asked her if she knew of any churches that are accepting, and she mentioned the Unitarian church. When I got home, I asked my co-worker if she knew where there was a Unitarian church in Baton Rouge. She said she goes to the Unitarian church, and she invited me to go with her and her family.

> When I meet people, I think that they usually know that I have a disability. I don't try to hide it. I am proud of who I am, and people seem to be comfortable with me and my disability. I want people who are gay to feel like that, too, and to feel that they are welcome.

It is a really neat, accepting church. There is a lot of laughter, it's not always serious, and I like that. Now I am looking for groups at the church that I could join, like the Social Justice Committee. We think they need to know more about people with disabilities and other groups.

In New Orleans, I made other friends who are gay. I told one friend, who was also a colleague, that I would never use that against her if we had a disagreement. She had hinted that she was gay one time when I was in the hospital, and mentioned that her lover and she were worried about me. I mentioned her lover's name, which she hadn't mentioned, and she said, "Yes." So then we could talk about it together. It hurts sometimes, because people will attack my friends about being gay—maybe they might just think they are gay, but they don't know for sure, and so they will make ignorant remarks. I just tell them they shouldn't be prejudiced about people who are gay. I don't admit that my friend is gay, I just talk about the prejudice. I want to protect my gay friends because they have trusted me with that information.

I have a lot of memories of times I have shared with my gay friends. I was really touched once when one of my gay friends invited me and my brother, who also has disabilities, to a Christmas party where almost everyone was gay. It was a great party, really fun. We did a mystery-type thing, and we went house to house to solve the mystery. It was my last Christmas party with them because I was getting ready to move to Louisiana for my new job. I remember another time when I was in Washington, D.C. with Bonnie. We had some free time, and we tried to figure out what to do for fun. I told her I could do movies in Oklahoma, so let's do something different. We decided to go to an interactive play called "Shear Madness" at the Kennedy Center. I really got into it. We were supposed to solve a murder mystery by paying attention to the clues they gave. One of the characters was a hairdresser who was gay. During the show, I asked Bonnie whether that offended her. He was a stereotype in how he acted and talked. I don't think she had any problem with it. I was glad, because I was having so much fun.

In my mind, people are people. No matter what race you are, no matter whether you have disabilities or are gay. One of my friends here, who is white, just married a woman who is black. He is the Assistant Secretary of the Office of Citizens with Developmental Disabilities. One day he beeped me, and I thought someone wanted me for official business, but he told me that he and his fiance had discussed it and wanted me to be the best man for their wedding. I felt really good about that. We are good colleagues and now we are becoming good friends. He was always there for me from the time I moved here. In the early days of this project, I was struggling and he listened and helped me decide how to make things better. He supported me when I wanted to move to Baton Rouge, and it is working out really well.

I feel hurt when I realize that people have to hide their identity because sometimes I feel the same way. People with disabilities hide ourselves, too, sometimes. For example, when I am on the computer in a chat room, I never say that I have a disability. I want people to react to me the same as they do to anyone else. If I were to say that I had a disability, I am afraid that some people

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People are People

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would feel uncomfortable or wouldn't know how to deal with it. I remember one time I told someone in a chat room that I have a disability, and he thought I was lying. He accused me of just saying that so the ladies in the chat room would feel sorry for me.

> "Coming out helped me to understand discrimination from the inside out. I had already experienced personal discrimination as a mother of a child with a disability, but this was different. I realized quickly that I was equally as eager to have my friends with disabilities accept me as they were for my friendship, and was very glad that they did. I have found that they think deeply about the issue and want to share their thinking with others."
>
> *Bonnie Shoultz*

When I meet people in person, I think that they usually know that I have a disability, and I don't try to hide it. I am proud of who I am, and people seem to be comfortable with me and my disability. I would want people who are gay to feel like that, too, and that they are welcome. But this weekend, I saw a terrible television show that condemned gay people and made fun of them, in a religion service. It made me angry to see that, and I didn't understand. If the church teaches us to love one another, how can they make fun of and tease people who are gay?

I first met Herb Lovett at the TASH conference in San Francisco in 1995. We had a chance to talk, and I realized that he was a neat person. I thought it was great that he was finding positive ways of helping people with disabilities so they wouldn't have to depend so much on drugs. We saw each other once a year at the conferences, and I also saw him two weeks before he passed away, in New Orleans. He was doing a training session for state employees, but I was invited to it, too. That's when we got to know each other better, because we went out to dinner and had a real chance to talk. I didn't know that he was gay. I first learned about that after he passed away. I wish he would have had confidence in me to tell me that, because I wouldn't have changed my opinion of him.

At the 1998 TASH conference, Herb's partner, Michael Dowling, accepted an award for Herb. He talked about their lives together and about how hard it had been for Herb to let people know he was gay and had been with Michael for so many years. I think he said Herb finally did that at a training he did several years ago. I went to the memorial we had for Herb on the evening of the day Michael talked. It was very powerful. I especially remember Michael talking about how disappointed Herb was to find out that his parents had voted against a gay rights referendum in Maine. It made me think of my own parents, because they aren't real supportive of what I am doing in Louisiana. I help people with disabilities learn to speak up for themselves, but they don't seem to want to see my world. I think they are ashamed of me and my brother Joe, who also has disabilities. When I heard the story about Herb's parents, I thought they were ashamed of that part of him. Then later, after he died, they realized that their shame had hurt him.

Sometimes I don't understand why my aunt is so supportive of Joe and me, but my parents aren't. My aunt is my real mother's sister. My mother died when I was 17. My aunt went to the Young Leaders' Conference put on by the President's Committee on Mental Retardation two years in a row. The first time she was there to see me get an award, and the second time to see me chair the conference and to see Joe get an award. I paid her way the first time, and she came as my guest. She paid her own way the second time. I was afraid to ask my parents to come, because I thought they would say "No, we are too busy." I wish my parents were as supportive as my aunt is. It hurts when that support and understanding aren't there from the people who mean so much to you. I know how Herb felt.

Bonnie: I have been an advisor for Self Advocates Becoming Empowered since before it had a name, and have been involved with the movement since 1975. I came out as a lesbian in 1985, after many years as a straight woman. I was 43 years old at the time, and had many friends with disabilities to do with whether I should try to hide my new identity from friends with disabilities. I assumed that they might reject me or at least disapprove, and that would have been very hard to bear. I did tell people with disabilities, and others found out through the grapevine. For the most part, people with disabilities have been accepting. All of those I consider my friends accept me as I am, whether I am with a man, a woman, or no one, though some have had to think about it a great deal because they had been taught to reject and condemn gay people.

Making the decision to be "out" was good for me. It also taught me a great deal. I learned that being in the closet is difficult mentally and emotionally. I learned that if someone was my friend, he or she usually appreciated my confidence in them, and that we became closer if I disclosed things about my life just as they did about theirs. And I found out that because most people with disabilities have many, many interactions with non-heterosexual people (and with people who are racially different from them), they have many opportunities to come to terms with how they feel about differences other than those along the ability spectrum.

I was single for four and a half years, but recently began seeing a man. It was much easier for me to tell my friends with disabilities about this than many of my gay and lesbian friends (and certainly

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Excerpts from 1999 Keynote Address: Anne Donnellan

Absence of Evidence: Myths about Autism and Mental Retardation

"If you want to know your myths, show me the people with whom you associate."
Joseph Campbell

Ah, humility. That's a good word to begin this talk about our field, the field of developmental disability, of mental retardation/autism. (I'll use these terms interchangeably because the labels don't really matter for this topic). We should be so humble and yet we are anything but. One reason is that this field is so dominated by myth. We have so many myths and they are so nested inside of each other that it was very hard for me to pull them apart. I hope I can make it clear to you even though they don't separate out very neatly.

We have myths about our vast progress in knowledge and understanding when what we need is humility in the face of how little we actually know about the people we serve. We have a notion that in naming something "mental retardation" or "autism" or "cognitive disability" or "severe handicaps" or "developmental disability"(or whatever our present euphemism to explain or define something we really don't understand) we have begun to understand the experience of individuals who have that label. On top of that we have a myth suggesting that in comparing such individuals to people without disabilities and finding the many ways they differ from us, we have clarified something about them. We seem to have forgotten the dictum: "Absence of evidence is not evidence of absence." That is, we have forgotten that testing somebody and finding what they cannot do doesn't tell us anything about what they can do under other conditions and doesn't necessarily tell us anything else about them. Yet, we continue to talk about people in terms of labels that come from testing outcomes as if these were real and useful.

Imagine if I tested you in Russian and found you could not, at least at that moment, speak Russian. Surely, I wouldn't then be able to say much about your potential as a tennis player or how best to develop the rest of your knowledge and skills. But that's pretty much how our field presently works and it works that way because we are still stuck with old ideas and myths.

The entire notion of "measuring" people's capacity and labeling and grouping them based on our results is not a 20th century model. It's a 19th century model that we're still using as we enter the 21st century and the new millennium. Basically, what we did starting in the 1800's, a century characterized by imperialism, is that we colonized people with disabilities. In fact, in my state, Wisconsin, and others, we literally called institutions where we incarcerated people with disabilities "colonies" much as nations referred to the places they dominated as colonies. And, as with all imperialistic systems, we developed mythologies around the people whom we colonized which helped reinforce the idea that they were better off as a result of having us run their lives.

It's these mythologies that I'd like to talk about for a few moments. Many of the myths come about because we forgot that scientific dictum I mentioned a moment ago: absence of evidence is not evidence of absence. There was a British-American television program recently called the Human Quest. In it, a well known professional was shown testing an 11-year old labeled with autism. The child failed a test that a "normal" child of four would likely pass with ease. The professional said (based on this and similar tests he had done) that:

"Children with autism are not reading behavior in terms of mental state. They're not showing any evidence that they possess concepts such as thinking, dreaming, imagining; the whole mental state realm."

Millions of people learned this about children with autism. So, let's follow this logic. Based on what they don't do, under very artificial and contrived circumstances, we can say what else these kids can't do, don't know, don't want, and so forth. In this case, the myth - the story we tell - is that they don't possess the ability we call "Theory of Mind," they don't possess the concepts of thinking or dreaming or imagining. Now, interestingly, that's not what the people with autism tell us about themselves. The person with the label of autism — in the film *A is for Autism* — clearly has some notion of the thoughts of others about him and how that got in the way of his playing with kids:

"Other kids wouldn't let me join in their game even though I wanted to because they thought I was mad, crazy, because I had tensed up and I had a way of flapping my hands and it came across as different and kids don't like kids who are different."

We talk about children and adults with the label of autism in terms not only of their lack of understanding about other people, but also their lack of interest in the rest of us. Yet, when they are asked, like this man, they tell us that they really want a connection with others but couldn't always handle that connection. Also in the film *A is for Autism*, Temple Grandin, a Ph.D. who has the label of autism, says:

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Absence of Evidence: Myths About Autism/Mental Retardation

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> ***Often we don't even see the people because we are too interested in seeing their behavior and their inabilities. "...Look at them from their terms and you may get some answers. Look at them from your terms and you will see only what you want to see."***

"As a child I wanted to feel the comfort of being held. I craved tender touching. At the same time, I withdrew from touch. Being hugged was like being swallowed by a tidal wave."

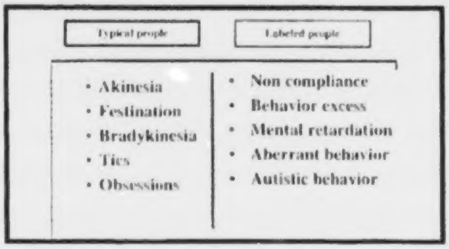
She craved affection like the rest of the babies in the world, but she couldn't handle it. We couldn't know that because she couldn't tell us. Donna Williams, another person with the label of autism, suggests this:

"Look at them from their terms and you may get some answers. Look at them from your terms and you will see only what you want to see."

Unfortunately, like all good imperialists, we have a tendency to look at events primarily from our own perspective and not the perspective of those whom we have colonized. If you talk to the folks with the disability, (what a concept!) you might actually find out what's true about someone. Of course, sometimes you can't do it just by talking. Sometimes you have to do what Herb Lovett told us to do in his last book. You have to be Learning to Listen: If the person communicates differently, you have to listen differently. But, we don't do that very much or very well. Moreover, we tend to believe that if information comes from our research and our science, especially if it has numbers and graphs attached to it, it's more valuable than if we talk to people. Often we don't even see the people because we are too interested in seeing their behavior and their inabilities. I hope I don't sound too scolding because I know a lot of our very good people are here. But even those of us who think of ourselves as good guys have to examine our own myths, or we won't contribute to real progress for the people that we are supposed to be serving.

We have a major and very basic myth that there is such a thing as autism, there is such a thing as mental retardation, and more than that, that we're getting better and better at understanding these things called mental retardation and autism. We are trapped by our own myths. Let's look at autism. First of all, it's not a thing. Yet, we talk about it as a "thing"(e.g. the child "has" autism) and think that this "thing" then both defines and explains the phenomena. So, here's how it works in practice. I've heard this story a million times. Parents bring in a child and tell the doctor: "My son rocks and he spins and he echoes and he can't talk or she does this and that" and after a suitable amount of time pondering, we experts say: "Ah ha! This kid has autism."

When the mother and father recover they ask questions such as: "Well, but why is my child spinning and rocking and echoing?" And the answer is: "Because he has autism." How is it that we know he has autism? Well, he spins and he rocks and he echoes and so forth. We don't get very far past that. We never ask the question: "Why does this child rock?" "Or, if he can echo, why can't he talk?" This is not a small point even though I try to make it humorous. It is very serious business because it causes us to look at people with the label of autism as very different from the rest of us. Then we mistake the labels for reality and forget that we barely understand the mere theoretical constructs or stories that help us talk about the phenomenon. What happens next is that our stories become common knowledge. Once they are common knowledge, they don't get talked about any more but they do get operated upon. Look at the slide at the top of the following column:



Typical people	Labeled people
• Akinesia	• Non compliance
• Festination	• Behavior excess
• Bradykinesia	• Mental retardation
• Tics	• Aberrant behavior
• Obsessions	• Autistic behavior

The very same behavior that might be called for the rest of us, akinesia, or the inability to move, would be called non-compliance if the person has a developmental disability such as autism.

Bradykinesia is another poorly understood phenomenon. It's about very, very, very slow movement. It can occur in many neurological conditions. One famous story comes from a person with post-encephalitic Parkinsonism in Oliver Sack's famous book, Awakenings. Sometimes he would have his finger under his nose for hours. When he was able to speak after being given the drug L-Dopa, the doctor asked why he did it. He said "What are you talking about? I was wiping my nose!" From his perspective, because the effects of the encephalitis so changed his perception of time and space, he was merely wiping his nose. He thought it took a second or so. It sometimes took three hours. So, from the "outside view" (our perspective) it was three hours; from the "inside view" (his perspective) one or two seconds.

Not only do we not consider this possibility, but if a person has a developmental disability label, we probably don't even see bradykinesia. Yet, there is literature demonstrating that problems such akinesia and bradykinesia are found in people labeled autistic. So we don't stop to think about what it would be like to struggle with problems such as akinetic episodes. And we continue to test and interact with people as if their poor performance were merely a matter of poor understanding or lack of cooperation due to their autism or their mental retardation. Then we mistake the data we accumulate from our specialized, expert,

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Absence of Evidence: Myths About Autism/Mental Retardation

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professional, objective stance as a special, expert and privileged kind of knowledge, a privileged reality, that helps to explain the phenomenon that we poorly understood in the first place.

In the last two years of this organization's journal, JASH, for example, most of the empirical articles dealing with disabled participants referred to them by their IQ scores and/or other test driven labels (example "profoundly retarded") as if these were real and meaningful and useful. What is that saying to the world at large? And, what is that saying to us about our knowledge base? It's saying that mental retardation is a measurable variable that helps explain the experience and behavior of the individual. It's something that someone "has" so we say he has mental retardation or cognitive disability. (By the way, it is also something that never leaves the person. I have never heard the sentence, "the formerly retarded Mr. Jones.") It explains why somebody can't learn. It explains why our programs fail and it explains, for my purposes, since I'm very interested in movement differences, why they move differently.

Movement differences or sensory-movement problems include difficulties in starting, stopping, executing, continuing, combining movements of perception, emotion, action or posture or thought as Martha Leary and I explain in our book on the topic. Some people argue that folks with autism don't have problems in movement, even motor action. Rather, some professionals claim that individuals with autism are remarkably well coordinated physically despite the fact they are often recognizably different from a football field away. Some of these people actually think we made movement differences up to explain facilitated communication.

> *If we are to make real changes in our field, we have to begin by realizing that autism and mental retardation may be how we label their experience, but really it's a label for our experience.*

In an article two years ago in Mental Retardation, Martha Leary and David Hill showed that there were hundreds of references to movement difficulties in the autism literature long before facilitated communication came on the scene. There's also a very good study on autism that was just out last year showing that folks with autism have difficulty with action, with moving their bodies. Not only are they not well coordinated, they are quite clumsy. Perhaps the most interesting comment, however, comes at the end of the article (and, remember, it's a good article). The authors say that those with higher I.Q.'s had fewer movement problems which, they suggest,, is probably a function of their higher intelligence. Now, it seems to me that if your ability to move well is a function of your cognitive ability, if I want to find really bright students at the University of Wisconsin I should go straight to the football team! They're certainly moving well; they're even moving to the Rose Bowl this year.

With every part of our received knowledge base we should do what my colleague, Michael Apple, says. We must "question the unquestionable." We must question the very roots of our field. One of those roots comes from the hierarchial models of the brain from a century ago which suggested that the "smart part" of our brains, that part which we do not share with the animals and which made our brains so big, is in charge of the rest of the brain and body. Thus, if your body isn't working right, it's because there's something less smart about you! We are so used to the idea that we never challenge it and, more important, we have ceased to look for the real relationship between movement challenges and the ability to score well on our IQ tests, never mind the ability to perform well in every day life. All this mythology contributes to the notion that we can assess objectively and, moreover, in our assessment we can come to know and understand someone and their experience.

If we are to make real changes in our field, we have to begin by realizing that autism and mental retardation may be how we label their experience, but really it's a label for our experience. For example, you all look at this picture [there is a slide of a woman sitting in a chair] and you immediately get a sense, a "hit" about the woman in the picture. Can somebody tell me what sense you get from the picture? [Responses from the audience: "Sad, depressed, withdrawn."] Does anybody think this is a happy person?[Answer: "No."] I agree. To me this is not a happy picture. Does anybody know this woman? [Response, "No."] Neither do I, but I've shown this to about 15,000 people and they almost all agree with us. We all agree but the truth is we don't know anything about her. What we're doing is assessing our experience, how we would be feeling if we looked like that. We have to begin to look at things from the experience of the other person. The only people who have ever given me a different answer are people with developmental disability labels who say things like: "Maybe she's watching TV;" or, most recently, "She's listening to the wind coming through the window." We have to start being honest and humble about the fact that we are very limited in our ability to assess people with severe communication difficulties. Instead of getting better and better at knowing them with our tests and checklists we may be merely getting better and better at agreeing with one another.

In the same way, we have consensus that autism/mental retardation are mind phenomena alone, that is, psychological and cognitive. Also, that somehow the minds and bodies of these folks are not connected except in some mysterious way so that the less smart you are, the less able you are to make your body work. So sure are we of this fact that we believe we can assume that lack of

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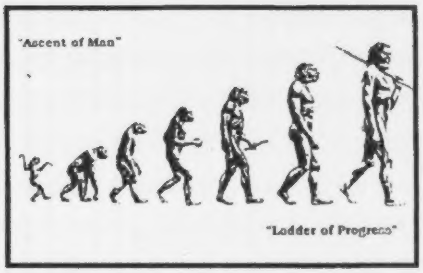
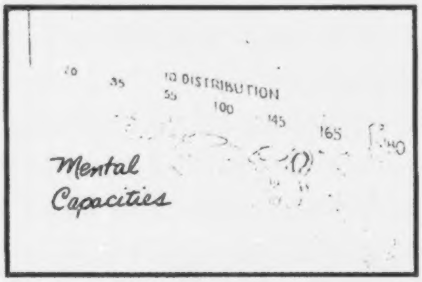
response on tests is due solely to mind problems.

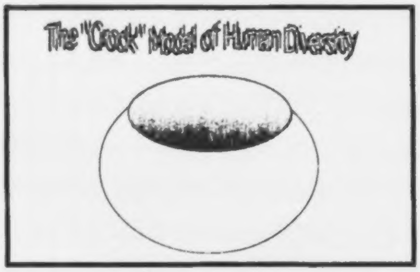
Mental measurement started in the middle of the 19th century as a reaction to Darwin; to the notion that somehow we were connected to the rest of the animal kingdom in some evolutionary way.



The original name for the idea of evolution was development. But, from this reaction to evolution came the notion that there were stages of development or evolution. Moreover, that evolution was for the purpose of getting to perfection, which is this last person here, who is white, Anglo-Saxon, upper middle class, educated, money owning, property owning, and male. This is not really a true depiction of Darwin's theory, of course, but this is what was believed because it helped people handle the very notion of evolution. Again, remember this is the age of imperialism. They absolutely believed in hierarchy. If there was to be a connection to the rest of the phylum (a direct line of descent within a group), it had to be a hierarchical relationship. According to Stephen J. Gould's wonderful book, The Mismeasure of Man, one of the things the white educated, upper middle class, rich, propertied men did to prove how much superior they were to other creatures is to say: "let's measure intelligence." If intelligence is the thing, and it must be because we gave it a name and know it's real, it must reside some place. Where do we think intelligence resides? In the head, of course. So they measured heads for 30 years to show that they were more intelligent than other, lesser humans. These were not a fringe group of individuals. Very famous people did this work. They dug up famous people, filled their skulls with sand, measured the heads of smart and not so smart people who were alive and came up with all kinds of numbers. It didn't work, of course. Their problem was that some black people had big heads and some women had big heads and some very smart folks had small heads. It didn't work, but they kept doing it and when they finally gave up on that version of the measuring intelligence enterprise, in flew the I.Q. model to take its place.

IQ tests are founded on the same premise. That is, that intelligence is a thing which can be measured within a hierarchical, linear model, and talked about in terms of space and distance and length and capacity of filling up an empty space. It's as though the glorious human intellect, knowledge and development were a matter of filling up vessels or crocks. So, in this slide there's the normate there in the middle and there's the retardate down here and as you can see the crocks get smaller and smaller as we get into the "retardation" range. This is the crock model of development. It's the crock model of human diversity. It is a crock.




The "Crock" Model of Human Diversity

Now, it would be funny if we didn't really believe it. We talk about intelligence and knowledge in terms of capacity and levels as if we were filling somebody up. We talk about stages as if you actually get some place, some real space, or platform, or point or that we arrive at some developmental destination and are then able to continue the journey to the next stage. There is no such thing as a real stage of development, of course. It comes from a 19th century idea stressing the discontinuity between ourselves and other primates. But, the idea was picked up immediately by psychoanalysts. And then by those who saw themselves as the scientists of measurement. We'll get to that in just a moment.

Meantime, in discussing IQ we must recall those who picked up on testing and measurement and other awful ideas to try to keep the hoards of immigrants from coming into the country. In the United States we really bought into the IQ story big time. It was built on a very racist model that assumed that the other races were an earlier stage of development, were inferior and measurably so. Those who remember the recent ballyhoo over the book The Bell Curve must surely realize that we are still living with the racist legacy of the crock model. We still are living with the notion that there is such a thing as measurability of intellect — that you can measure a concept! And that, at least in terms of those we label as mentally retarded, there are those who can be shown to be not quite human, but pre-humans who fail to come up to our standard. That's a very important notion in the underbelly of our field. In fact, people who we would today call severely and profoundly disabled in the 19th century were considered the living archeological record of pre-human existence. An interim stage in evolutionary history. Throwbacks. Back then they were even categorized by Langdon Down as representative of a more primitive race, the "Mongoloid" race. We are not so many years away from the term Mongoloid and, more to the point, we have institutionalized many of these biases and beliefs in our present day attitudes, as we can see in this slide. As

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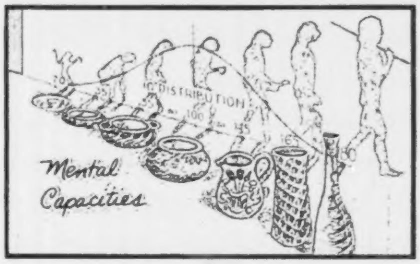
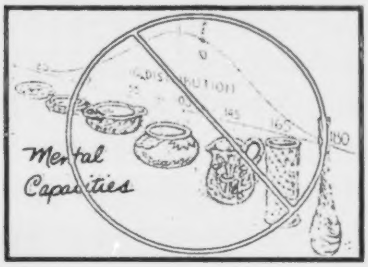
Bob Williams suggests, the result is: "We have severe ignorance and profound misunderstanding."



I'd like now to show a tiny little piece of tape of Sue Rubin. Sue Rubin was a keynote speaker here at TASH last year and I just want those who weren't at the conference to see and hear her for just a moment.

Sue Rubin on tape: *"I'm interested in mental retardation and autism. My interest stems from the fact that until I was 13, I was thought to have an I.Q. of 24. I am presently a senior at Whittier High School with a GPA of 3.85. Clearly, something is amiss."*

Today, Sue is actually a student at Whittier College with a GPA of nearly 4.0. She types with facilitation. She also often types independently. She ought to cause us to ask: "What exactly is mental retardation?" At the risk of offending, I want to say that when I was at TASH last year and Sue presented and independently answered questions, yet "looked" for all the world as if she were a person with an I.Q. below freezing, when she let us know that she got 725 on her math SAT's and a scholarship to college, I don't know why the entire audience and the entire TASH organization didn't rise up and say: "What are we doing?" "What are we talking about?" "What is it we actually know about the people we claim to represent?"



Instead, many left that talk unconcerned, perhaps comfortable with the notion that Sue is just the exception. She's not like the people we work with. Don't get me wrong. I don't think all the people we work with can get 725. At least one of us at this microphone couldn't get anything like 725 on the math SAT. But I'm smart enough to know that we have woven so many myths into our profession that soon we'll have to do our work on a combination word processor and food processor in case we have to eat our words. Alternatively, we can stop and say: "A lot of this story we tell is a crock and it isn't working." We can no longer pretend to know and understand people who are labeled by comparing them to us "normates" as we've been doing for 150 years. Certainly, I'm not suggesting that people with disabilities are really "OK." Of course many people have significant problems. My point is that we are not getting better at understanding the problems of each unique individual or accommodating them. Moreover, I am saying we cannot continue to do and say and write things which contribute to the notion that these are less than human beings who deserve attitudes or treatment that we would not tolerate for ourselves, our loved ones or our fellow humans.

As a case in point, this is picture of a shock device, a cattle prod. One state is now advertising that, as part of a training program, they can provide "a fun filled day" and a lot of food and teach you to use this kind of remote control cattle prod against people with disabilities. The slide comes from a flyer for a device upon which the newer shock delivery devices were based. It says under the picture of a little girl wearing the device: "This not offered for sale to control people." No. Only those with disabilities.

Okay, let me sum up this part. What we think is that we know what normal is and what developmental stages equate to normal and how far the "autistic" or "retarded" are from normal. In fact, our model and our data base is actually very inadequate. So, even while we congratulate ourselves about all the things we've done and we are doing very good things — certainly many people in this organization are doing very good things with supports and getting funding and programs and so forth — we really don't know who the people are that we're talking about. It's time we start understanding the people whom we label as having a development difference or cognitive disability. There is a lot of literature out there to help us learn more. I will talk about this for only two minutes. If you miss it, don't worry. I'm editing a new book with Michael Weiss for Academic Press in which we will have a meeting of the minds the best thinkers in autism with the most cutting edge thinkers in child development. We call the book Autism and Pervasive Developmental Disorders: Shifting Paradigms and New Perspectives and expect to get it out in 2001...a date that seems appropriate for the topic!

There are new paradigms of development and we must begin to incorporate these into our knowledge base. There's nothing wrong with the Applied Behavioral Analysis approach, but it cannot continue to be the major and dominant scientific paradigm of our field. It's inadequate. It's not good enough. It's a good tool that helps at times but explains very little. We have to stop thinking of people as computers that we're filling up with data and programming. We have got to start thinking in terms of the chaos theory (or bio-dynamical systems) which has begun to document the complexity of the human development. The human brain is the most complex object in the universe. It doesn't necessarily become less complex by virtue of a developmental difference. Yet, we talk about it as if this were so. I believe we thought they [the children and adults that we support] were simple-minded so we created simple-minded explanations.

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In a new paradigm we acknowledge that there is no hierarchy for how body and brain work. There is no conductor up there. The cortex, the "smart part" of the brain, is not in charge, is not running the show. The individual is a self-organized dynamical system and the brain is part of that system with all parts working in concert, sort of like a jazz ensemble which has no conductor. And, if you have a very unusual developmental history it's going to work but it's going to work in very unusual ways and the rest of us are going to have to begin to understand those ways. To do this we have to start including the work of people like Edelman and Thelen and Kelso into our literature and into our field. They can help us understand that development doesn't follow a single predictable course. It has to happen online, with experience, in the moment. The genes can constrain development but it is what happens during development that drives development. Development occurs in context. Knowledge is flow as you move from context to context. You have softly assembled bundles of abilities, knowledge and skills and you bundle and rebundle them as the context changes and makes them useful for you.

What it means is that, quite literally, every child is unique, every word is unique, every movement is unique. Replication is impossible. We can try but we can't really replicate. And we can't assume that ability or lack thereof in one context is evidence of lack of other abilities or lack of ability in all other contexts. As an example of uniqueness, and of the fact that there is no genetically pre-determined preprogram or course of development, consider these two little girls from Minnesota who are conjoined twins. How could you possibly have a preprogram for development in conjoined twins? These girls were not predicted to be able to do anything, even sit up. Yet they are able to learn to walk, ride a bike, tie their shoes, do gymnastics and swim. Note, they are actually two little girls who share the lower part of a body. Each has a brain that operates with half the body. They are a unique self-organized system just like the rest of us and just like everybody we represent who has a label.

To sum up, learning is development; it doesn't wait for development. What we do is bring forward softly assembled bundles of abilities/knowledge/skills at any given moment depending on the context. And context is everything. As Gregory Bateson told us, context is not just what's left over when we pull out the part that we want to study. It's everything. It's your history. It's that person's history. It's that person's body. It's what's happening in the room at that instant and what happened a moment ago. This is in large part Esther Thelen's work and these are her words:

"Action cannot be separated from perception from the bio-mechanics of the limbs and from the nervous system which generate the control of movement. Likewise, perception and action form the basis of cognition and are inextricably implicated in social and emotional development."

Now we will put on the film so you can see just how complex and dynamic this story really is. The film is of a person, Dr. Tom Riese, with a condition called "Parkinson's Disorder." He is a physician. He was 35 years old when he developed Parkinsonian symptoms. Sometimes he cannot move. Listen to what he says on the film about when he's akinetic. He tells us that akinesia is not just not being able to physically move, but one's cognition changes and one's ability to interact and so forth.

Narrator of the film: *"As he tried to understand the riddle of his disorder, he experienced the well known effect of kinesia paradoxa. By following a pattern of objects like stairs, he could temporarily escape the halting gate so typical of Parkinson's called Akinesia."*

Dr. Tom Riese says: *"I just was very determined to find out what was unique about stairs that allowed one to walk that was different from the rest of the environment and I experimented with simulated stairs with objects, first,large objects then progressively smaller objects. It finally got down to the point where I could use pennies and dimes and tiny little marks on the floor to simulate objects and that was having the same effect as the stairs."*

Narrator: *It is a kind of trick the eye plays on the brain allowing it to tap into a more primitive form of behavior. Only when the pattern was extended into space could the patient walk again."*

The doctor goes on to say: *"I would love to shop at Safeway because they have the 12x12 inch linoleum tiles and I could use that as a grid and those kinds of environments are wonderful. They're not universal."*

Narrator: *"Unable to sleep at night or walk without over medicating himself with the drug L-Dopa, Riese became obsessed to find a way to permanently extend those life saving patterns."*

The doctor then discovers glasses that operate on the principles of virtual reality.

Dr.Tom Riese: *"I read about this product and I realized that one could superimpose imagery onto reality without obliterating reality which was an important distinction. One could see the real world and one could effect it by putting objects onto the ground in front of oneself. When one is akinetic, there is not just the lack of walking. There is a whole spillover effect of problems. One is stiff. One has the feeling of being under water. One's mental acuity seems to deteriorate."* (Emphasis added).

Narrator: *"When the VR sports glasses were modified. they simulated the effect called Kinesia Paradoxa, paradoxical movement. What Tom Riese saw when he put on the glasses was a series of moving objects projected infinitely into space."* The film then shows the doctor walking almost effortlessly.

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Dr Tom Riese: *"When one walks with the [virtual reality perceptual] cues, all that lifts and melts away. It's not just gaining the ability to walk, it's gaining these other spillover effects which are very, very liberating."*

Dr. Riese's experience is the living embodiment of a new axiom: "We cannot move without perception, we cannot perceive without movement." It's all part of a new paradigm of the biodynamics of development and we must begin to understand what it means for individuals with significant developmental differences. What we are beginning to know from new research is that knowledge/skills/behavior are softly assembled bundles that appear or disappear in context. So, for example, here is my friend, Aaron Ulrich, whose mom, Mary, is here, a former board member of TASH. This is his signature. This is his signature on the bottom, three minutes later when he used the little squiggly pen that gave him a vibrating feedback as he wrote. [Signature went from large scrawl to being neat, clear and appropriate size]. Now, I'm afraid that Special Ed will say that it's the model for everybody. Squiggly pens are the next cure. No, don't do it. Don't buy squiggly yet. I'll make special educational squiggly pens and make a million dollars. I'm joking, of course. The point is: The pen works for him in that context. That's all we can say besides "Maybe it will work for someone else in some context," but not automatically just because he and someone else share the same label or accumulated the same number of IQ points.

Similarly, maybe everybody doesn't need just pictures on their communication board. Lots of people can use words to communicate and lots of people can use the alphabet. Maybe not everybody. But some people and many we never expected. And we won't know who's who by giving them standardized tests or by testing them in ways that completely distorts the context in which they were able to use words in the first place. We don't know what will work for any given person, but we've got to start by trying lots of things and looking at people in context one person at a time.

If we don't start examining our myths, we'll end up just living with our myths and misconceptions and make no real change in how we know and feel about people. It doesn't matter if we use the autism word, the mental retardation label or some other euphanism as long as our attitudes are limiting people. And they are. I can speak for myself; mine certainly are. And as long as our attitudes go unexamined, the people we represent are in trouble. We have to stop thinking about mind and intelligence in terms of space, a crock, a thing with size, as something that we have or don't have, program or fill or don't fill, or can only fill so much or in a certain prescribed way.

That's our job. Let's do it! Thank you.

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People are People

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easier than talking about it in the TASH *Newsletter!*). One of the most difficult things was having to rethink my assumptions about what "group" I belong to. I knew intellectually that all categories are socially constructed, but having lived as a member of two categories (straight and lesbian), I have felt the effects of self-labelling as well as labelling by other people, and I felt that I belonged with the queer (or gay/lesbian/bisexual/transgender) community. Luckily for me, the queer community is increasingly including people who identify as bisexual as well as transgendered people.

Coming out helped me to understand discrimination from the inside out. I had already experienced personal discrimination as a mother of a child with a disability, but this was different. I realized quickly that I was equally as eager to have my friends with disabilities accept me as they were for my friendship, and was very glad that they did. I have found that they think deeply about the issue and want to share their thinking with others. James approached me about this article, for example, and after he and I agreed to write it, two of our other friends on the SABE Board also wanted to write. I have also found that I deeply respect the process my friends with disabilities have used to come to their conclusions.

As James said, "People are prejudiced against us and we know how that feels. So why would you want to do that to them?"

Questions or requests for additional information may be addressed to the authors. Contact James at 225-927-0855 or Bonnie at 315-443-4323.

Individuals with Significant Disabilities and Consent to Sexual Activity

BY JAMES K. McAFEE AND PAMELA WOLFE

Background and Concepts

Webster's New World dictionary defines consent as "to give assent or approval." In the context of sexuality and persons with cognitive disabilities, the issue of consent is clearly intertwined with the legal issues of competence and protection from abuse and exploitation. The latter point is especially critical when we consider the fact that solicitation for prostitution is one of the most common crimes with which persons with developmental disabilities are charged and sexual abuse of persons with developmental disabilities is a pervasive social problem. The court in Gray v. Grunnagle (423 Pa 144, 1966) defined consent as "... an act of reason, accompanied with deliberation, the mind weighing as in balance the good and bad on each side. It means voluntary agreement by a person in the possession and exercise of sufficient mentality to make an intelligent choice to do something proposed by another... ."

Lest we view persons with disabilities only as the objects of sexual offers, sexual consent must be examined in three forms: (a) the right to say no to a request from another, (b) the right to say yes to a request from another, and (c) the right to initiate a request. The three aspects may be viewed in an educational and developmental sense. First, individuals learn how to protect themselves from predatory, inappropriate or undesired advances. Second, individuals learn about entering into voluntary relationships that may have sexual elements. Finally, individuals learn how to initiate interpersonal relationships that may have sexual elements.

Consent includes three components (a) knowingness - having sufficient information about the nature of the proposal of the other, (b) voluntariness - absence of coercion either positive (unreasonable inducement) or negative (threats of loss), and (c) competence - the ability to use the knowledge and consider outcomes (potential consequences and strategic thinking about short and long-term possibilities) (Burgdorf & Spicer, 1983).

The complexity of consent is further multiplied by the vagaries of law. According to Mezer and Rheingold (1962) there are over 100 legal definitions of competence. Determinations of competence are influenced by age, physical and mental capacity, and situation.

Obviously, the age variable in competence to consent is determined for the most part by statutory law. Thus, states promulgate standards for the age of consent. The second concept — capacity — is ever changing because better and more effective education, combined with opportunity to practice decision-making, has resulted in higher estimates of capacity. This change is evidenced in the abrogation of statutes that formerly permitted wholesale sterilization of classes of citizens (persons with mental retardation, epilepsy and other disabilities) merely because they belonged to the class.

Today, it is unlikely that a statute would stand the tests of discrimination on the basis of disability if it automatically permitted denial of self-determination rights to a class of citizens (i.e., those whose IQ is below a predetermined cutoff). Capacity decisions are more appropriately made on the basis of the individual's experience, history and performance in the face of similar consent demands. Furthermore, determination of capacity to consent is temporal. It is amenable to instruction and learning. Statutory definitions of capacity to consent vary widely from state to state, but generally include understanding the physiological nature of the act and/or understanding the moral nature of the act (Slavis & Walker-Hirsch, 1999).

Finally, situational considerations are critical to analysis of the need for external interference (i.e., control by parent, guardian, agency or court) in the individual's freedom to consent (or to deny consent). The AAMR (formerly the American Association on Mental Retardation) published a small text entitled A Guide to Consent in which Slavis and Walker-Hirsch outline the situational aspects of consent to sexual activity. According to Slavis and Walker-Hirsch, professionals must develop a balance between traditional roles as protectors of persons with developmental disabilities and their more contemporary roles as advocates for the right to exercise choice. This balance is ever-changing because of changes in mores, laws and knowledge about the ability of persons with developmental disabilities to make reasonable choices.

The right to make choices about sexuality and sexual expression is interpreted as a privacy right from the Bill of Rights. Furthermore, the AAMR 1992 redefinition of mental retardation emphasizes the need for varying levels of support to move individuals toward greater autonomy. Thus, capacity to consent is dynamic, situational and modifiable. Slavis and Walker-Hirsch provide a hierarchical analysis of sexual situations

> Professionals, family members and persons with developmental disabilities who seek to improve capacity to consent and, hence, expand the array of sexual experience must realize that development of capacity to consent begins in infancy. It arises from experience, experimentation, explicit instruction, incidental learning and the positive reinforcement of success and the lessons of failure and opportunity to try again.

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Individuals with Significant Disabilities and Consent to Sexual Activity

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upon which differential standards for capacity to consent may be based. At the lowest level are those activities that are not generally regulated. This includes solitary activities (masturbation and access to certain erotic material) and pre-sexual activities such as dancing and friendship.

The issues for professionals at this level are appropriateness (e.g., public masturbation) as opposed to potential for harm. At this level, familial and professional intervention is appropriately limited to teaching the appropriate choices for time, place and circumstances. At the next level are activities that involve mutual consent, for example, activities such as petting and sexual stimulation by another. At this level, the appropriate role of professionals includes the instruction in the aforementioned appropriate choice for time, place and circumstances and the development of understanding of mutuality. The latter point is critical and mutuality requires an understanding that both persons enter into the relationship freely, may withdraw freely, and that neither has the right to offer inducement or threaten harm as a means of initiating or sustaining the relationship.

At the highest level of consent are those activities for which potential outcomes threaten safety. The primary activity at this level is sexual intercourse. Potential damaging outcomes include pregnancy, sexually transmitted diseases (STD), and criminal charges (for prostitution, pandering, rape, and assault). At this level, professionals and family members must consider appropriate choice of circumstances, mutuality, and the ability to act safely and legally. The last two components, safety and legality are most complex. Therefore, capacity to consent to sexual intercourse is measured by the individual's demonstrated behaviors related to appropriate birth control and reduction of STD risks. Capacity is also related to understanding the legal restrictions placed on sexual intercourse. These include sex for compensation (prostitution), pedophilia (sex with a minor) , involuntary sex (rape and assault), public sex (indecent and lewd behavior), and statutory restrictions on sexual relations with a person who doesn't have the capacity to consent.

Assessing Capacity to Consent

Slavis and Walker-Hirsch offer a list of 23 dimensions on which capacity to consent should be assessed. They include: knowledge of sexual activities, understanding of wrongful sexual behavior, understanding of rights, understanding of consequences of sexual behavior, understanding of mutuality, ability to seek assistance and understanding appropriate context for sexual behavior. The reader is directed to the discussion in the Slavis and Walker-Hirsch chapter for more details.

Programming for Capacity to Consent

> **Consent to sexual activity is a complex legal, social, behavioral and instructional issue. Professionals, parents, and persons with developmental disabilities who are interested in improving capacity to consent should include family members and persons with developmental disabilities in the development of policies, curricula and implementation.**

The capacity to consent is developed over an extended period of time. For persons who do not have cognitive disabilities, the legal assumption is that the capacity is developed upon reaching the age of majority (generally 18). Obviously, some individuals may achieve the capacity (meaning understanding) to consent earlier than 18. However, the law provides few exceptions (marriage). In contrast, some individuals may never demonstrate the behaviors indicative of responsible sexuality. They may engage in risky behavior although they understand the risks or they may never fully understand the risks.

Professionals, family members and persons with developmental disabilities who seek to improve capacity to consent and, hence, expand the array of sexual experience must realize that development of capacity to consent begins in infancy. It arises from experience, experimentation, explicit instruction, incidental learning and the positive reinforcement of success and the lessons of failure and opportunity to try again. Thus, it would be foolish to develop a capacity/consent curriculum that is implemented only upon attainment of adolescence or adulthood. On the other hand, to expect sexual competence to arise in the absence of instruction is even more imprudent.

Schweir and Hingsburger (2000) describe the development of sexual competence for persons with intellectual disabilities. The text is specifically designed for parents of persons with intellectual disabilities, but the content is at least partially adaptable to professional instruction. Their text progresses through developmental experiences that enhance sexual competence and hence capacity to consent. Topics include modesty, peer pressure, homosexuality, abuse, saying no, marriage and family, and financial and legal consequences.

Not all persons with intellectual disabilities have had the opportunity to develop sexual competence through a natural developmental process. In fact, based upon widely reported criminal statistics, we know that persons with intellectual disabilities are often prosecuted for sexual crimes that indicate lack of sexual competence(see for example, Shapiro, 1986). Thus, more formal programs are required and it is beyond the scope of this article to detail such programs. The content is relatively easy to identify. The

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aforementioned list of 23 areas provided by Slavis and Walker-Hirsch is certainly a good foundation for a curriculum. However, good content is a necessary but insufficient condition for development of capacity to consent. Additional essential conditions include opportunities to practice newly learned behaviors in appropriate contexts and assessment of understanding. Obviously, privacy needs preclude direct observation and feedback and some individuals may choose not to engage in sexual activity. Discussion of situations, group analysis of appropriate responses to sexual situations and individual follow up to difficulties are effective procedures.

Over the past 30 years, the authors have had the opportunity to be involved in several programs designed to promote self-determination. In one such program, Linda, a 32 year old woman with a mild intellectual disability sought emancipation from a program and from a guardianship that had been enacted during her early adolescence. At a competency hearing, her sister (who was her guardian) challenged Linda's capacity. The primary point of contention was Linda's capacity to consent to sexual activity. This was especially critical because Linda had announced intent to marry. Linda's responses to the judge were articulate, specific and to the point. One question put to her was, "What will you do if you become pregnant?" Linda's response shocked most of those in attendance. She stated, "That is not a concern because my sister had me sterilized when I was fifteen!" A check of medical records indicated that Linda's response was accurate. Her response also indicated that she had knowledge of her own sexual situation beyond that which others anticipated because to the best of our knowledge, none of the professionals working with Linda were aware of her state. Linda's sister testified that she had never told Linda about the purpose of the surgery. The culminating exchange in the hearing was one in which the attorney for the sister attempted to downplay Linda's apt responses by asking her if she had been coached. Linda's response was, "I have been taught, and I have learned." Linda's emancipation was granted.

Conclusions

Consent to sexual activity is a complex legal, social, behavioral and instructional issue. Professionals, parents and persons with developmental disabilities who are interested in improving capacity to consent should:

1. Understand the legal nature of consent.

2. Understand the differing situational demands for capacity to consent.

3. Teach sexual competence throughout development.

4. Understand that risk must be balanced with opportunity to grow.

5. Provide increasingly complex opportunities for choice.

6. Provide opportunities for feedback and analysis of choice including legal, financial, and strategic consequences.

7. Maintain documentation of criteria used to determine capacity to consent.

8. Maintain documentation of intervention and educational efforts.

9. Include family and persons with developmental disabilities in the development of policies, curricula and implementation.

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TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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Newsletter

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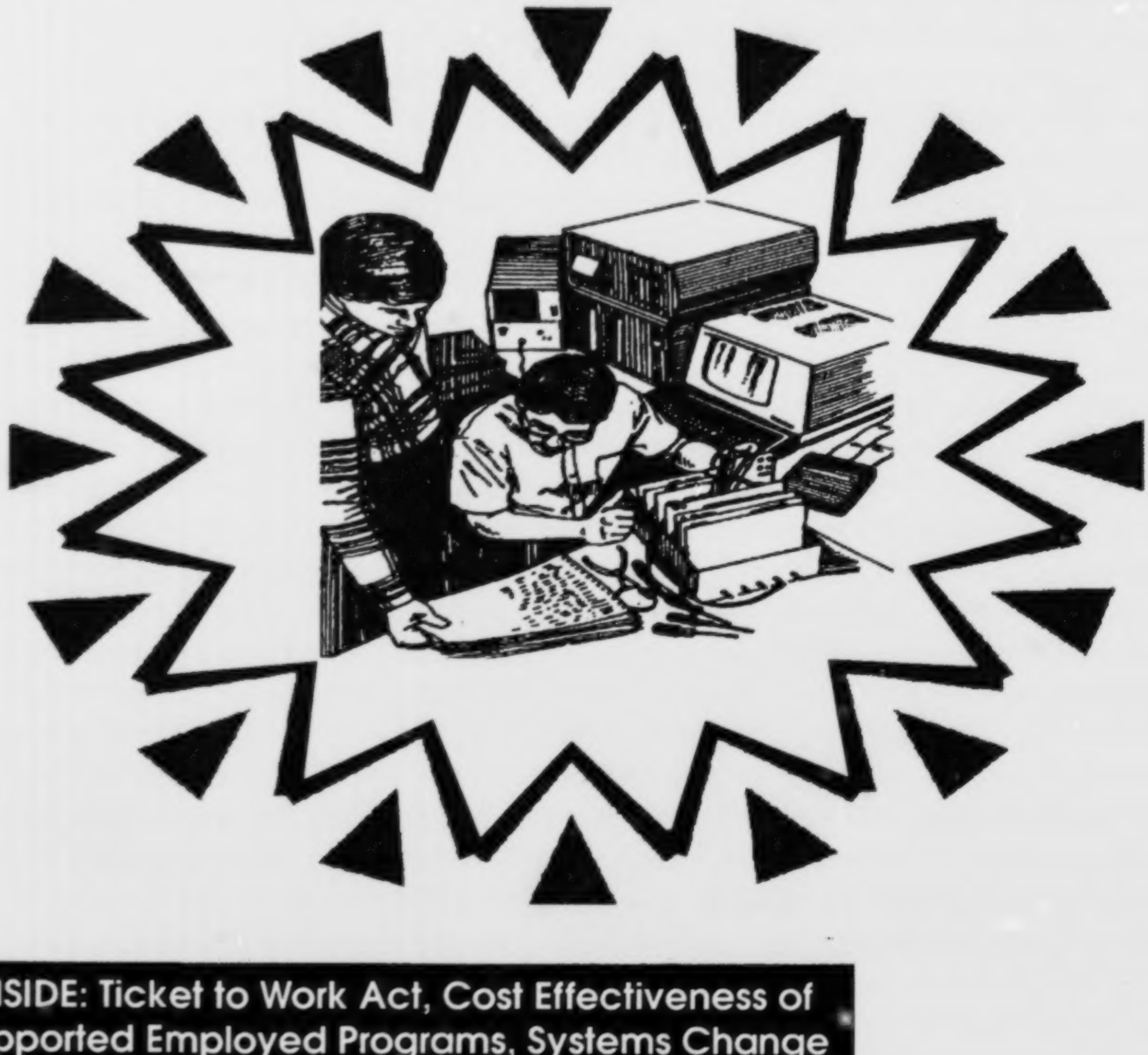
Issues in Supported Employment



INSIDE: Ticket to Work Act, Cost Effectiveness of Supported Employed Programs, Systems Change and Supported Employment, and TASH Resolution on Peace

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;
~
Building communities in which no one is segregated and everyone belongs;
~
Forging new alliances that embrace diversity;
~
Advocating for opportunities and rights;
~
Eradicating injustices and inequities;
~
Supporting research and disseminating knowledge and information;
~
Promoting inclusive education;
~
Supporting progressive legislation and litigation; and,
~
Promoting excellence in services.

An Invitation to Participate

The U.S. Department of Education's Office of Special Education Programs (OSEP) is soliciting input on improving results for infants, toddlers, and children with disabilities. If you are an individual with a disability, parent, professional educator, member of a national educational or advocacy organization, policymaker, researcher, or other stakeholder concerned with special education issues, then OSEP wants to know your opinions.

Information will be used by OSEP to develop a long-range, comprehensive plan for its IDEA National Program (Part D of the Individuals with Disabilities Education Act). The plan will identify national activities for linking best practices to states, school systems, and families to improve results for children and youth with disabilities.

How to Participate

- Web site -- The survey is available at: **<www.OSEPplanning.org>** You may complete it online.
- Print survey -- To request a survey, please call 1-800-510-1668 (TTY: 1-800-813-5812), send e-mail to OSEPplanning@westat.com, or write to Westat at: Westat, Inc., OSEP Comprehensive Planning Project, 1009 Slater Road, Suite 110, Durham, N.C. 27703

IDEAs that Work

U.S. Office of Special Education Programs

Note from the Editor: We wish to thank the many people who responded to our request for personal stories from and about people with disabilities and their work experiences. The response was so great that we plan to publish a special section on supported employment stories later this Fall. If you have a personal story about supported employment and/or transition issues that you would like to share with the TASH readership, please submit it for consideration to Priscilla Newton at <pnewton@tash.org>

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
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MARCH FOR JUSTICE

We're Voting for Our Lives!

Monday October 2, 2000 - 12:00 Noon
Upper Senate Park - Washington, DC

Join thousands of civil rights advocates for a rally to support the American's with Disabilities Act (ADA). This fall the United States Supreme Court will be hearing arguments in the case of Garrett v. University of Alabama, which calls into question the constitutionality of the ADA. The civil rights of millions of people with disabilities hang in the balance while we await the decision.

This is not just a case about disability rights - it is about everyone's civil rights. There are no guarantees in life and anyone may find themselves facing the injustice of discrimination by an employer or lack of access, because of a disability or even a serious illness such as cancer, asthma, or HIV/AIDS. Without the protections that the ADA provides to guard against injustices in the workplace and community, everyone in America is faced with the threat of losing their civil rights.

The rally will take place just 36 days before the election of the next President of the United States. The next President will be in position to appoint several new Supreme Court Justices during his term. The decisions that the next group of Supreme Court Justices will hand down will affect the civil rights of all Americans for generations. We need to make sure that the Presidential candidates are aware that we will voting our hearts and minds in favor of justice for all!

So make plans now to come to Washington D.C. on the first Monday in October – the opening day of the Supreme Court session – to join with other advocates for justice and with our combined voices we will send a loud and clear message to our elected officials, and candidates that we are "VOTING FOR OUR LIVES" this election.

If you are unable to attend the event in Washington DC, contact Andrew Imparato at AAPD to learn how you can organize an event in your hometown.

So come to Washington DC on October 2 or participate in a local event and let our message be heard. **And remember!!!** Be sure to encourage your families, neighbors, and friends to get out and VOTE FOR THEIR LIVES on November 7.

Sponsoring organizations of the ***March For Justice***:

- American Association of Persons with Disabilities - AAPD
- ADAPT
- Disability Rights Education and Defense Fund – DREDF
- Disability Rights Center
- National Association of People with AIDS
- National Association of Protection and Advocacy Systems – NAPAS
- National Council on Independent Living – NCIL
- National Parent Network on Disabilities – NPND
- TASH: Disability Advocacy Worldwide

From the Executive Director
BY NANCY WEISS

Let Freedom Ring

On Sunday, June 18th, TASH participated in a rally in Washington, D.C. that was attended by over 800 disability advocates from across the country. The rally called for Congress to pass S. 1935, the Medicaid Community Attendant Services and Supports Act (MiCASSA). MiCASSA, introduced by Senator Tom Harkin (D-IA) and co-sponsored by Senator Arlen Specter (R-PA), is a bipartisan bill which would allow people to choose to live and to receive services and supports in the community; a choice they lack under current institutionally-biased Medicaid policy. The rally was marked by a renewed commitment to cross-disability advocacy to fight together for changes that will benefit all people with disabilities.

I spoke at this rally representing TASH. My remarks follow:

"My name is Nancy Weiss. I am here representing TASH, an international disability advocacy association that is unique. TASH is not a professional association; it is not a parent organization; nor is it an association of self-advocates — rather, it is the only organization I know that is a true coming together of all three. TASH's members are people with disabilities, family members, and people who work in the disability field in all capacities, worldwide.

TASH envisions a future in which equal opportunity will be the norm; in which children with disabilities and children who do not have disabilities will be educated side-by-side; in which all children will be provided the supports they individually need to be successful. TASH envisions a world in which adults with disabilities, and those without, having grown up side-by-side as children, will live together as co-workers, neighbors, and friends.

TASH celebrates the growing trend among disability organizations toward a true cross-disability focus. One of the messages I want you to take home today is that people with mental retardation and other developmental disabilities are no less angry. They no more want to live in institutions than anyone else and they no more need to live in institutions than anyone else. They will no longer accept institutions and other congregate living situations as their only options.

It has served those who would see people with disabilities kept down well to keep disability groups apart and to fan the flames of conflict and competition among disability communities. Today's rally for MiCASSA is living proof that we will no longer allow our power to be diffused by allowing ourselves to be splintered into competing camps.

All people with disabilities and their friends, family members, and advocates share common goals - and these don't seem like too much to ask:

❖ *To be given a fair shake;*
❖ *To be given the same opportunities as everyone else; and,*
❖ *To given the same access to the American dream as every other citizen of this great county.*

Ask a group of any Americans what their goals are for their golden years - not a group of people with disabilities - just your average group of guys playing cards, the parents of the PTA, a group of little league coaches - and not one person will say 'to spend them in a nursing home.' It's not that a minority of Americans want eventually to live in a nursing home, it's not that only a small percentage of Americans hope one day to live out their lives in a nursing home...try this. Ask your friends, neighbors and co-workers. NOT ONE person in your survey will mention life in a nursing home as one of his/her goals.

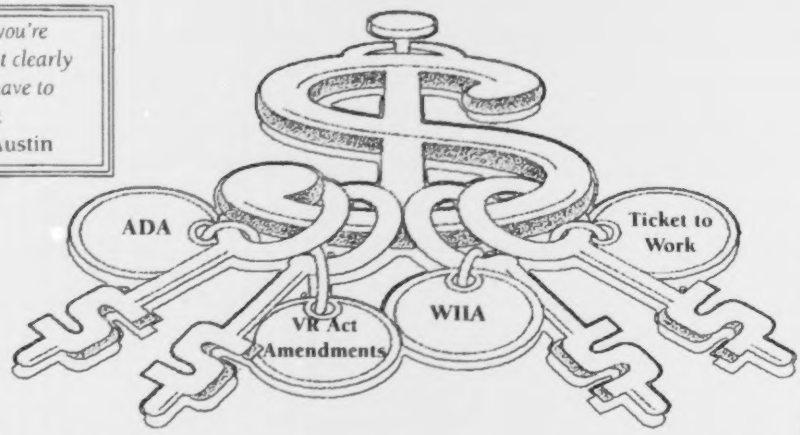
So how did we get where we are today? How did we get to where nursing homes or institutions are the only available choices for people with complex needs for support when no one - given options, would choose them? It sure wasn't people with disabilities who came up with this plan!

But people with disabilities have come up with a plan — a new plan — and it's called MiCASSA. And what's brilliant about this new plan called MiCASSA is that it benefits everybody. It benefits people with physical disabilities who have been stuck in nursing homes. And it benefits equally people with mental retardation and other developmental disabilities who have been shut away in institutions without a voice and without a chance. Not only does it benefit people who need complex supports today — it benefits all Americans — because anyone who is not institutionalized today or at risk of being institutionalized today is only temporarily out on bail. All Americans face the risk of being institutionalized as we age.

We of the disability community have found our strength not only in numbers, not only in the commonalities that bind us together, but today, in logic. What could be more logical:

Take an approach that no American would chose for him or herself and make a new plan. Turn it around so that CHOICE, rather than CONTROL, is the cornerstone of the new plan. Give every American equal access to the American dream and let freedom ring - not just for the young, not just for the educated, not just for the able-bodied, but for ALL. Let Freedom Ring!"

> *You have to know where you're going, to be able to state it clearly and concisely - and you have to care about it passionately.*
> Tom Peters & Nancy Austin



Are we there yet? Trends in Employment Opportunities and Supports

BY JOHN BUTTERWORTH AND DANA GILMORE

Over the past several years there has been increasing national emphasis on the participation of individuals with disabilities in the labor force. This concern was highlighted by the establishment of the Presidential Task Force on Employment of Adults with Disabilities by Executive Order on March 13, 1998. The Task Force has as its mission "to create a coordinated and aggressive policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population." A variety of recent legislation and policy changes address employment opportunities. The Workforce Investment Act of 1998 was implemented with a broad goal of consolidating, coordinating, and improving all national workforce development initiatives, including vocational rehabilitation and youth employment programs. The Americans with Disabilities Act, the Ticket to Work and Work Incentives Improvement Act of 1999, amendments to the Vocational Rehabilitation Act, and changes to Medicaid regulations are all intended to expand access to employment.

Despite these and other policy initiatives on both the state and federal level, employment trends continue to carry both good news and bad news. This summary will review current information about employment trends on a national level for the general population and for state MR/DD and VR agencies, the largest sources of employment support for individuals with significant disabilities.

General Employment Trends

Individuals with disabilities participate in the labor force at consistently lower rates than individuals without disabilities.

Data from the current population survey suggest that over the ten years between 1987 and 1997 labor force participation for both men and women with disabilities declined, despite the economic boom in the mid to late 1990's. These data are summarized in Table 1.

Table 1: Labor Force Participation
Data adapted from Burkhauser et. al (1999)

	1987	1992	1997
Men w/o disabilities	96.1%	94.8%	95.2%
Men w/ disabilities	44%	41.6%	35.5%
Women w/o disabilities	77.1%	77.6%	80.7%
Women w/ disabilities	37.5%	34.3%	31.9%

Poor labor force participation is, of course, only part of the story. Individuals with disabilities experience both underemployment and high rates of poverty. The median annual earned income for individuals with disabilities is as much as one third lower than their nondisabled peers, and individuals who are working are disproportionately participating in entry level and service industry jobs that have not benefited from the economic boom. In 1997 the median annual earnings of men with disabilities was $10,562 compared to $30,466 for men without disabilities. Women with disabilities had median annual earnings of $8,124, compared to $20,311 for women without disabilities.

Data on poverty and disabilities are consistent with the employment data. Based on family income, 25% of men with disabilities and 32% of women with disabilities lived in families with an income below the poverty line. Poverty has and continues to be closely related to disability. A recent study appearing in the New England Journal of Medicine raises questions as to whether disability leads to poverty or poverty to disability. This study notes that living with prolonged economic hardship affects people much like a major chronic disease by limiting physical and mental ability and impinging on routine activities of daily living (Lynch, Kaplan & Shema, 1997).

As labor needs grow and the workforce changes, companies are indicating a growing concern with supporting a diverse workforce in responsive ways. Growth in the percent of individuals from diverse cultures, women, and individuals over the age of 65, are leading to a growing emphasis on flexibility and work/family supports. All of these changes should lead to increased

Continued on page 6

Trends in Employment Opportunities and Supports

Continued from page 5

flexibility and opportunity for employees with disabilities.

State MR/DD Agency Services

State MR/DD agencies provide, fund, or monitor a wide range of day and employment services for individuals in the community service system. These services include employment supports, traditional facility based options including sheltered workshops and non-work day habilitation programs, community integration services, and more individualized options. The Institute for Community Inclusion has collected data on trends in day and employment services funded or monitored by state MR/DD agencies since FY88. Data is currently available for FY88 through FY96.

National data provided by state MR/DD agencies indicate that while the number of individuals in integrated employment has increased dramatically, with almost 100,000 individuals reported in integrated employment in FY96, there is wide variation from state to state in employment participation. In fact, individual state reports vary from a low of 4% participating in integrated employment to a high of 60% in integrated employment. Nevertheless some states have made dramatic change. In FY96, five states (Colorado, Connecticut, Minnesota, New Hampshire, and Washington) reported that over 40% of their participants in day and employment services were in integrated employment, suggesting that substantial systems change is occurring in some states.

Major trends through FY96 indicate that:

◆ ***MR/DD agencies significantly expanded their capacity to provide day and employment services*** during these eight years, supporting almost 398,000 individuals in FY96. This represents an increase of 40% or 110,000 individuals from FY88.

◆ ***Supported employment has expanded steadily.*** The number in integrated employment increased by over 200% from 32,471 in 1988 to 98,315 in 1996. Concurrently the percent of individuals who participate in integrated employment has risen from 14% to 26% of all individuals receiving day and employment services.

◆ *Maintenance of dual systems.* Despite the significant growth in integrated employment, these data show continuing growth in the number of individuals supported in facility-based and non-work services. The total number of individuals in facility-based and non-work services increased in real numbers during this period from 242,102 in FY88 to an estimated 320,359 in FY96, an almost 12% increase.

◆ ***Individuals are more likely to use multiple services or settings.*** There are increasing reports of individuals who receive multiple services simultaneously dividing their time between a community job and other service options. This is a significant change from FY88 when most individuals were in a clearly designated service category.

◆ ***Community-based non-work services are expanding.*** Finally, states are increasingly reporting community-based non-work (or community integration) as a service category, and this option was included for the first time in these data in FY96. These services represented 16% of the overall services reported by states in FY96, despite the fact that not all states reported them.

State VR Services

State Vocational Rehabilitation (VR) agencies provide services to over one million individuals annually, with approximately 600,000 individuals completing services and having their case closed in each fiscal year. Approximately 12% of those individuals completing services in each year can be identified as having a developmental disability, the focus of the data reported here. The last 15 years have been a time of significant policy change for the VR system. The 1986 amendments to the Rehabilitation Act defined and established funding for supported employment, while the 1992 and 1998 amendments extended VR's commitment to competitive employment outcomes for individuals with the most significant disabilities and strengthened consumer participation in the rehabilitation process. During this period there has been steady improvement in the employment outcomes of individuals with developmental disabilities in the VR system. Four trends were particularly significant:

1. ***The total number of individuals exiting VR services and rate of successful closures has remained steady.*** The total number of individuals with mental retardation and developmental disabilities completing VR services (having their cases closed) has stayed remarkably stable between FY85 and FY98, ranging from a high of of 73,736 to a low of 67,638. Similarly, the percent of successful closures, individuals who achieved a rehabilitation goal, was consistent at between 46% and 48% of the individuals who exited VR services for each of the years. A closure considered successful by VR can include a variety of outcomes, including competitive employment, sheltered employment, or self-employment. In FY98, 86% of the successful closures were in competitive employment, and 12% were in sheltered employment.

> Despite positive change, the majority of service system resources continue to support facility-based or other non-work services.

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Trends in Employment Opportunities and Supports

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2. **Entry into competitive employment has increased.** There has been a steady increase in the number and percent of individuals entering competitive employment. This change is evident across all levels of disability, and in particular the percent of individuals with moderate and severe mental retardation entering competive employment increased from 52% in FY85 to 78% in FY98.

3. **Real wages and hours worked have declined.** While the mean weekly earnings of individuals with mental retardation and developmental disabilities who entered competitive employment with VR support has remained relatively stable between FY85 and FY98, when wages are adjusted for inflation there has been a significant decline in real earnings. Average weekly earnings grew from $143 per week in FY85 to $166 per week in FY98. After adjusting for inflation, mean weekly earnings in 1985 dollars declined by 51% from $143 in FY85 to $82 in FY98, a substantial decrease in real income. The mean number of hours worked during each week at the time of closure declined from 34.6 hours/week in FY85 to 28 hours/week in FY98.

4. **Supported employment services continue to rise, but rely on Title VIc funds.** The number of successful closures for individuals with developmental disabilities identified as receiving supported employment services increased by 86% between FY91 and FY98, rising to almost 10,000 in FY98. The majority of individuals who received supported employment services, 67% in FY98, continue to receive at least some of their funding from Title VIc (funds dedicated to supported employment). While the use of Title 1 funds (core VR resources) is steadily increasing, supported employment services are still not fully integrated into the mainstream of services funded under Title 1 of the Rehabilitation Act.

Summary

These trends represent both good news and bad news in the effort to expand access to employment. There is clear continued growth in the number of individuals in integrated employment, and there are increasing opportunities for flexibility, creativity, and consumer-direction in day and employment services. At the same time, facility-based and non-work services have continued to grow nationally, raising concerns about the service system's commitment to the goal of integrated employment. Similarly, the growth of community-based non-work services raises questions about the clarity of the service systems commitment to employment as a primary goal. The VR system has substantially increased the number of individuals entering competitive employment with the support of rehabilitation services. Of more concern is the quality of the employment that individuals are entering. The decrease in wages after adjustment for inflation and the decrease in hours worked have a real impact on quality of life. Developing policy and service strategies that expand both the diversity and quality of employment opportunities are important goals.

Despite positive change, the majority of service system resources continue to support facility-based or other non-work services. Both state agencies and individual service providers will need to revisit and clarify their commitment to employment services through organizational goals and policy in order to maintain expansion of employment opportunities.

Note: This manuscript was supported, in part, by cooperative agreement # 90D0032, from the Administration on Developmental Disabilities, Administration for Children and Families, Department of Health and Human Services, and grant # H133B980037 from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

Resources

Detailed data on state and national trends between FY88 and FY96 are available in the 1999 ICI monograph, State trends in employment services for people with developmental disabilities: Multiyear comparisons based on state MR/DD agency and vocational rehabilitation (RSA) data. The monograph is available for $20 including shipping. For information on ordering contact Emily Barrett at (617) 355-6506 or by email at <barrett_e@a1.tch.harvard.edu>.

Burkhauser, R. V., Daly, M. C., & Houtenville, A. J. C. (1999). How Working Age People With Disabilities Fared Over the 1990's Business Cycle. Ithaca, NY: Cornell University, Rehabilitation Research and Training Center for Economic Research on Employment Policy for Persons with Disabilities. Available on line at <http://www.ilr.cornell.edu/rrtc/papers.html>

John Butterworth and Dana Gilmore work with the Institute for Community Inclusion at Children's Hospital and the University of Massachusetts in Boston. For more information, please call (617) 355-7074 or you may send an e-mail to:
butterworth@a1.tch.harvard.edu

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Trends in Employment Opportunities and Supports

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One-Stops & WIA

The implementation of the Workforce Investment Act (WIA) is set to occur on July 1st. WIA replaces the Job Training Partnership Act (JTPA) and covers the general workforce and training systems in this country, including the One-Stop system. (Vocational Rehabilitation is among the mandated partners in the One-Stop system.)

To help in the exchange of information with the disability community about the new workforce system, a message board on One-Stop Centers and the Workforce Investment Act (WIA) has been developed by the Institute for Community Inclusion. The purpose of this message board is to provide a forum for exchange of information on disability-related issues pertaining to WIA and One-Stops. Among the areas that the message board will cover are:

☐ Questions concerning the use of One-Stop Centers by people with disabilities

☐ The opportunities available for people with disabilities under WIA

☐ Sharing of experiences in using One-Stop Centers by the disability community

☐ Tips for people with disabilities in using One-Stop Centers

☐ Any other issues related to WIA & One-Stops of interest to the disability community

Please feel free to visit the message board to add your input and to find out what's happening with the implementation of WIA. You can access the message board at: www.childrenshospital.org/ici/wiaforum/

Direct Service Staff Needed

Growing non-profit seeks staff to support a young boy with developmental disabilities in Silver Spring, Maryland home

Responsibilities include:

implementing and monitoring care plans, and

forming partnership with family of child to provide supports at home and in community

Requires a BS degree and evening/weekend hours.

Previous experience supporting children with developmental disabilities preferred. Excellent salary and benefits.

Send resume to:

SEEC, Human Resources
707 Conservation Lane
Gaithersburg, Maryland 20878
Fax: 301-527-0119
E-mail: SEECHR@aol.com

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JASH

Call for Papers

Sexuality and sexual expression are natural and important aspects of our everyday lives. Yet, for people labeled with severe disabilities, opportunities for sexual expression are often overlooked, under supported, or outright denied. Moreover, people with significant support needs often fall victim to sexual assault and abuse. Sexuality and sexual expression are important concerns for all people, but until recently the topic has been given little attention for individuals who require the most support to express their sexual desires, communicate affection toward others, and enter into fulfilling intimate relationships with partners of their choice.

JASH, the journal of TASH, invites contributions to a special series on Issues in Support of Sexuality to be co-edited by Linda M. Bambara (Lehigh University) and Ellen Brantlinger (Indiana University-Bloomington). Specifically, JASH invites research studies (quantitative and qualitative), policy analyses, concept/position papers, reviews of the literature, and program or curriculum descriptions.

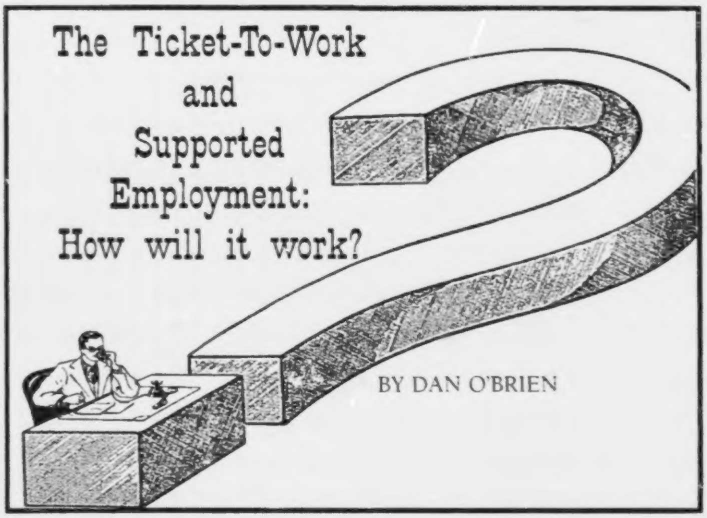
In addition, JASH seeks short personal reflection papers by parents, self-advocates, and other participants in the disability field for the Exchange section of the journal. Exchange manuscripts will be evaluated according to their contribution to the discussion of sexuality issues (author guidelines may be found on the inside back cover of JASH).

Papers submitted to JASH for possible publication as part of the special series should be preparedaccording to the Journal's author guidelines, and all submissions will be peer reviewed.

For additional information on the submission process, please contact:

Linda M. Bambara, JASH Editor, Lehigh University, College of Education, 111 Research Drive, Bethlehem, PA 18015 or send an e-mail to <linda.bambara@lehigh.edu>

The Ticket-To-Work and Supported Employment: How will it work?



BY DAN O'BRIEN

The Ticket-to-Work and Work Incentives Improvement Act signed by the President in December 1999 is intended to:

1) Increase beneficiary choice in obtaining rehabilitation and vocational services;

2) Remove barriers that require people with disabilities to choose between health care coverage and work; and

3) Insure that people with disabilities have the opportunity to participate in the workforce and reduce their dependence on public benefits.

Plan Overview

The disability community has welcomed the Ticket-to-Work ("Ticket") portion of the bill as an opportunity for self-determination and for people with significant disabilities to drive services rather than the reverse. The Ticket will give every SSI and SSDI recipient a voucher for the purchase of vocational services. The vouchers will be valued at a percentage of the estimated savings to the Social Security Trust Fund when a beneficiary returns to work and leaves the roles. The initial value was set by Congress at 40% of the estimated average savings. To insure adequate incentive to serve those with the most significant disabilities, the Commissioner of Social Security can adjust this figure. The SSI Ticket/voucher will initially be worth approximately $12,000 and the SSDI Ticket/voucher will have a value of approximately $18,000.

Beneficiaries will choose from SSA-approved providers and develop a plan of service with the provider. Existing SSA vocational service providers under the Alternate Participant [alternative providers to the VR (vocational rehabilitation) system] program will be automatically approved for the new system, as will State VR agencies and One-Stop Employment Centers. State Agencies will be considered a provider and will have to compete for the beneficiary's business.

There are over 600 existing providers nationally that fit one of these categories, so there will be some choice of provider from the first day. At the outset, the Ticket program will not be available everywhere. SSA plans to phase in all states and territories over a 3 year period. The first beneficiaries to have Tickets issued will be in the initial pilot states beginning January 1, 2001. The 12 pilot states are scheduled to be chosen by the end of the Summer or early Fall 2000. The SSA will contract with a Program Manager to issue the Tickets and manage the administration of the provider network. The Program Manager will be selected by the end of September 2000. The Program Manager will likely be one of several administrative service organizations with expertise in vocational services.

Impact on Existing Benefits

Naturally, those of us who have worked with or benefitted from supported employment programs wonder how this new system will effect or enhance the existing systems. My hope when I read the law was that this huge infusion of funding, up to $80 billion over the life of the program, would strengthen supported employment services because it provides for 60 months of payments to the provider for supporting the beneficiary's continued employment. My observation of most supported employment efforts is that the ongoing support of the worker to retain employment is the weakest link and greatly under-funded by the state partner agencies. The ongoing support of monthly payments from SSA --- for up to 60 months of employment --seemed to be the solution to this problem.

Details of the Plan

Unfortunately, as always, the deuce is in the details. The voucher payments would be made to the vendor in two parts, a series of "milestone" payments during the first 9 months of employment and then 60 monthly payments for retention of employment at SGA (substantial gainful activity). SGA is currently set at $700 per month. If the beneficiary does not make at least $700, no monthly payments would be made to the vocational service provider.

The milestone payments are meant to reduce the financial risk a provider of service has in serving the beneficiary. The cost of assisting a beneficiary to obtain 9 months of employment can be quite high depending on the individual's level of need. States that have existing milestone payment systems for supported employment report that the cost of 6 to 9 months of placement, training and employment support ranges from $5,000 to $12,000 for individuals with signifi-

> Disability advocates should monitor the implementation of the "Ticket" law in their state and actively work to overcome any limitations of the law.
>
> Changes are likely to be needed to the legislation when the exact nature of potential discrimination against individuals with the greatest needs are clear.

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Ticket-to-Work and Supported Employment: How will it work?

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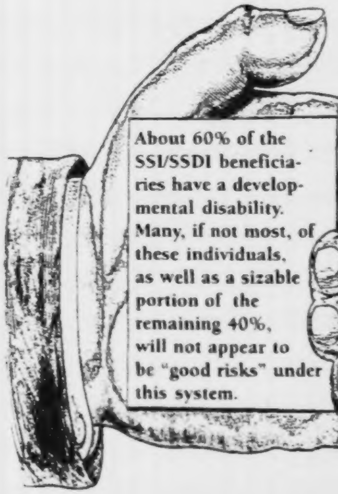
cant disabilities. In the vocational rehabilitation (VR) system nationally the cost of services to reach 9 months of substantial gainful activity is about $10,750 according to SSA's VR reimbursement figures. The milestone payment system, as used for supported employment, was intended to pay the full average cost of providing services, while simultaneously giving the customer/ consumer more control and a better quality outcome.

The Ticket use of milestones differs in that it is not intended to cover the full cost of the service. The Ticket will pay less than the cost so that the provider breaks even after about 2 to 4 years of employment. The provider will only breakeven if the consumer continues to work and does not receive a benefit check. In that instance, they receive the monthly payments in addition to the milestone payments for a maximum of 60 months. The 60 months of employment do not have to be consecutive. As yet, no rate has been set for the milestone payments, but the Congressional Budget Office (CBO) estimated that it would be set at $1,500 for 9 months of service. SSA will probably set the payment higher than CBO estimated but lower than the actual cost. The farther from the real cost the milestone payments get, the greater the incentive to "cream" or -- more accurately -- discriminate, against people with significant disabilities.



About 60% of the SSI/SSDI beneficiaries have a developmental disability. Many, if not most, of these individuals, as well as a sizable portion of the remaining 40%, will not appear to be "good risks" under this system.

Pitfalls of the Plan

SSA wants to leave the provider with a deficit at the end of 9 months of service with the only hope of breaking even being the ongoing monthly payments of $200-300. The theory is that because the provider's funds are "at risk," they will be more likely to insure that the beneficiary stays employed until the Trust Fund breaks even. The break-even point is where SSA saved more in benefits not paid to the recipient than they paid the provider. Because SSA is only paying out 40% of the estimated average savings, their breakeven point will be between 2 and 4 years of employment above substantial gainful activity (SGA). About 60% of the SSI/SSDI beneficiaries have a developmental disability. Many, if not most, of these individuals, as well as a sizable portion of the remaining 40%, will not appear to be "good risks" under this system.

There will be enormous pressures on providers to reject tickets from beneficiaries who "appear" unlikely to work at SGA for 4 years. Disability advocates have addressed this issue with SSA and they are listening. SSA's focus for right now is on getting the first states up and running in January 2001, not on addressing "possible" future problems. We need to keep the discussion going on this issue and watch very closely during the implementation phase. SSA will need feedback when the problems are clearer and real. What they can do to address these problems is two-fold:

- As part of the Ticket rollout, they could simultaneously establish pilot programs to address the needs of "high cost" individuals. One option is to pay a higher rate perhaps 50% of estimated savings for the higher cost individuals (defined below) and use the additional funds to make higher Milestone payments. This would reduce the amount of money the provider would be at risk for, i.e., has to go to the bank to borrow. This would reduce but not eliminate the pressure to discriminate.

Congress was concerned about this problem, as evidenced by the provision in the Ticket law requiring SSA to submit a report by Jan of 2003 on the "Adequacy of incentives for the provision of services for:

'(i) individuals with a need for ongoing support and services;
'(ii) individuals with a need for high-cost accommodations;
'(iii) individuals who earn a sub-minimum wage; and
'(iv) individuals who work and receive partial cash benefits."

- SSA or their Program Manager could encourage state MH/MR Authorities to establish Employment Networks which would provide Milestone funding to providers at rates which do cover the average cost of 9 months of service. Many states are already doing this by developing Supported Employment Milestone payment systems. The State MH/MR Authority would use existing or new vocational funding to finance the services and SSA would pay them under the Ticket program. The State program would thus take on the initial risk that SSA is not willing to shoulder, and small providers can't, and SSA would fund the ongoing support services with the monthly payments.

Close Monitoring is in Order

Advocates should be monitoring the implementation of the Ticket in their states and actively working to overcome the limitations of the law. Congress expects to have to revisit the law as implementation proceeds. Advocates warned Congress members and staff about these potential problems. Changes are likely to be needed to the legislation when the exact nature of the discrimination against high need individuals is clear.

2000 TASH Conference
"Moving the Edge"

December 6-9, 2000 ❖ The Fontainebleau Hilton Resort and Towers ❖ Miami Beach, Florida

2000 TASH Conference
moving the edge
Miami Beach, Florida - December 6-9th

Tentative Conference Agenda

Tuesday, December 5th
7:00 PM - 9:00 PM - Registration Open

Wednesday, December 6th
7:00 AM - 10:00 AM - Registration Open
9:00 AM - 4:00 PM - TASH Techs
3:00 PM - 7:00 PM - Registration Open
5:00 PM - 7:00 PM - Opening Reception

Thursday, December 7th
7:00 AM - 10:00 AM - Exhibitor set up
7:00 AM - 2:00 PM - Registration Open
8:30 AM - 10:00 AM - Opening Plenary
10:00 AM - 12:45 PM - Exhibits Open
10:30 AM - 12:45 PM - Breakout Sessions
1:00 PM - 2:15 PM - Roundtable /Box Lunch on the Grand Lawn
2:15 PM - 5:45 PM - Breakout Sessions
2:00 PM - 6:30 PM - Exhibits Open

Friday, December 8th
7:00 AM - 12:00 PM - Registration Open
8:00 AM - 10:15 AM - Breakout Sessions
10:00 AM - 7:00 PM - Exhibits Open
10:30 AM - 12:00 PM - General Session
12:15 PM - 5:00 PM - Breakout Sessions
5:00 PM - 7:00 PM - Gala 25th Anniversary Reception and Silent Auction in Exhibit Hall

Saturday, December 9th
7:30 AM -10:30 AM - Exhibits/Posters w/ Continental Breakfast
10:30 AM - 1:15 PM - Exhibit Hall Breakdown
10:00 AM - 1:30 PM - Breakout Sessions

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TASH members, as individuals, advocates, families, and professionals, are working together to pave the way and stretch the boundaries of the "cutting-edge" in supporting people with disabilities to live the lives of their choice -- as integral and meaningful members of the community.
Mark your calendars now to join over 2,500 people from all over the world at the internationally recognized TASH Annual Conference, *"Moving the Edge."* There will be over 350 sessions, exhibits, roundtable luncheons, and much more. Keep an eye on our web site <www.tash.org> for updates!

The Keynote Addresses:

TASH is privileged to welcome Nobel Peace laureate, Dr. Oscar Arias, to join us in Miami as one of our keynote speakers at the annual conference.
Dr. Arias is a visionary leader in the international community, promoting the organizational values reflected in the TASH Resolution on Peace (see page 15 of this *Newsletter*). Dr. Arias is also one of the primary authors of the Nobel Peace laureates' International Code of Conduct on Arms Transfers.

See the full text of the article, "TASH Joins with the International Community To Support Peace" beginning on page 14 of this newsletter.

"The Tiles Won't Stick Without the Grout"
Pat Mirenda

This keynote will employ the image of a mosaic to examine the changes that have occurred over the past 20 years with regard to the places in which people with significant disabilities live, work, play, and go to school. As the "tiles" of the mosaic change from segregated to community settings, the role of the "grout" that holds them in place is often misunderstood or overlooked. In particular, the roles of augmentative communication, literacy, and positive behavior supports as key elements of the "grout" that is essential to the integrity of the mosaic will be explored in detail.

Pat is an Associate Professor in the Department of Educational and Counseling Psychology and Special Education at the University of British Columbia. Previously, she was the Director of Research and Training for four years with CBI Consultants, a group that provides training and support for people with significant communication and/or behavior challenges. Dr. Mirenda lectures widely and teaches university courses on inclusive education, augmentative communication, autism, and supporting students with challenging behavior in schools. Her current research includes studies in the areas of positive school-wide discipline practices, computer technology for students with autism, and interventions for young children with autism spectrum disorders.

Official Conference Location and Hotel

Fontainebleau Hilton Resort and Towers
4441 Collins Avenue, Miami Beach,
Florida 33140
Phone: 305-538-2000

Special Conference Rates

Single Occupancy - $140.00
Double Occupancy - $80.00 per person;
$20.00 for each additional person

These rates are exclusive of tax. Please be sure to specify that you are with the TASH Conference. The TASH block is protected until November 6, 2000. After that date, you may still reserve rooms (if available), but they may be at a higher rate.

2000 TASH Conference Registration Costs must be paid in U.S. Funds. Full conference registration rates include: Full 3-day conference, all materials, two receptions, lunch on Thursday, and continental breakfast on Saturday.

Registration rates for TASH International Members:

$229 - Individual Registrant
$ 69 - Parent
$ 69 - Person with a disability
$169 - Student

One day only (Thurs., Fri., or Sat.)
$139

TASH Tech Pre-Conference Workshops
$ 55.00 - General
$ 40.00 - Parent/Self-Advocate Rate

Registration rates for TASH-Chapter Only or Non-Members:

$359 - Individual Registrant
$145 - Parent
$145 - Person with a disability
$259 - Student

One day only (Thurs., Fri. or Sat.)
$199

TASH Tech Pre-Conference Workshops
$ 85.00 - General
$ 60.00 - Parent/Self-Advocate Rate

TASH TECH Pre-Conference, Full-Day Workshops

Wednesday, December 6, 2000
The Fontainebleau Hilton
Miami Beach, Florida
9:00 AM - 4:00 PM

Plan to arrive in time to attend one of the highly informative and practical pre-conference workshops. TASH TECH workshops are interactive, and contain information that will redefine the edge in "cutting-edge" strategies for supporting people with disabilities to live, work, and play as meaningful members of their home communities.

Be sure to choose early, as sessions do fill up quickly! More information about each pre-conference will be available on TASH's website, in the conference brochure and in the September conference edition of TASH *Newsletter.*

T1- Movin On: Movement Differences and Behaviors That Challenge Us
Anne Donnellan, Martha Leary

T2- Love, Sex, and Relationships: The Journey to Joy for People with Developmental Disabilities
David Hingsburger

T3- Civil Rights, Self-Determination and Decision Making vs. Guardianship
Dohn Hoyle, Sally Burton-Hoyle, Kathleen Harris, Tom Nerney, Mayer Shevin

T4- Mind Play: Tools for Creativity
John Irvin

T-5 - Linking General Education Standards, IEPs and Inclusive Classroom Instruction
Cheryl M. Jorgensen

T-6 Developing Augmentative Communication to Support Participation in General Education Classrooms
Michael McSheehan, Rae Sonnenmeier

T-7 Collaborative Teamwork for Inclusive Education: Integrating Therapy and Educational Services
Beverly Rainforth

T-8 Designing and Implementing Inclusive Curriculum: Teaching Community and Standards
Mara Sapon -Shevin, Mary Fisher, Paula Kluth, Lucille Zeph

T-9 International Inclusion Update
Anne Smith, Roberto Leal, Zuhy Saheed, Diane Richler

T-10 Multiple Intelligences in Inclusive Classrooms
Robin Smith, Laurel Garrick Duhaney

T-11 Zen and the Art of Inclusive Recreation Design
Dan Wilkins, Cynthia Burkhour

T-12 Family, Support, Self-Determination and Disability
Susan Yuan

Special Symposium (co-sponsored by NADD):

S-1 Mental Health Aspect in Persons with Developmental Disabilities: An Overview of Dual Diagnosis

Free!

What's free and how can you take advantage of it? Why, registration for volunteers to this year's information-packed, exciting TASH Annual Conference in beautiful Miami Beach, Florida, of course!

If you would like to attend the conference and save on registration fees, this is the deal for you! As a volunteer, you donate a minimum of 10 hours of service during the conference in exchange for complimentary registration to attend any of the more than 350 sessions, workshops and discussion groups on topics ranging from Advocacy to Urban Education Issues and everything in between during your non-volunteer periods.

Whether you've participated as a volunteer before, or would like to do so for the first time, your services are urgently needed as a Conference Volunteer!

If you are interested in receiving more information or a volunteer application, please contact Priscilla Newton, Volunteer Coordinator, at 1-800-482-8274, ext. 102 or send an e-mail to <pnewton@tash.org>

SEE YOU IN MIAMI BEACH!

TASH

Conference in Canada??

The Conference Committee is looking into the possibility of holding a future year's conference in Canada. The exchange rate is such that hotel and meal costs would probably be reduced by more than one-third. Given that the costs would be lower, does your organization, school or university prohibit travel outside of the United States?

Please respond by telephone (1-800-482-8274, ext. 103) or e-mail <dmarsh@tash.org>.

Thanks for your input!

Silent AUCTION EVENT

Have you ever thought about the distinctive characteristics that make your state or country such a unique place in which to live? We would love for you to share the tastes, sights and sounds of your favorite places with others who may not have a chance to journey to your corner of the world.

Why not make a donation to the TASH Silent Auction?! Not only is the fair market value of all donations tax deductible, but proceeds from the auction will benefit the TASH Conference Scholarship Fund. The Fund is used to assist people with disabilities, parents and other family members to attend future TASH conferences.

If you would like to make a donation or find out more details, please contact Priscilla Newton, Director of Marketing, at 410-828-8274, ext. 102 or send an e-mail to pnewton@tash.org

TASH Joins with the International Community To Support Peace

BY CRAIG MICHAELS

"War, and the preparation for war, is one of the greatest obstacles to human progress. Violence does not resolve problems, rather, it fosters a vicious cycle of arms buildups, conflict, and poverty. Yet, instead of addressing the root causes of conflict, many states often utilize military might in order to control increasingly desperate populations. Many developing countries continue to be burdened by high percentages of their population living in misery.

Let us not forget the magnitude of the challenges that face us as we enter the 21st century. In today's world, nearly one billion people are illiterate, more than one billion lack access to potable water, and 1.3 billion earn less than $1 a day. Unfortunately, half of the world's governments dedicate more resources to defense expenditures than to health programs.

Imagine what we could do if a portion of world military spending was redirected toward investing in human development."

(Speech by Dr. Oscar Arias during the public signing of the Nobel Peace Laureates' International Code of Conduct on Arms Transfers-New York City, 29 May 1997.)

TASH is privileged to welcome Nobel Peace Laureate, Dr. Oscar Arias, to join us in Miami Beach as one of our keynote speakers at the annual conference. Dr. Arias is a visionary leader in the international community, promoting the organizational values reflected in the TASH Resolution on Peace (see page 15). Dr. Arias is also one of the primary authors of the Nobel Peace Laureates' International Code of Conduct on Arms Transfers.

Dr. Arias' keynote will provide guidance to conference participants as he responds to our newly adopted Resolution on Peace and highlights the work ahead for TASH. To quote further from Dr. Arias: "*world leaders must make human security the priority for the 21st century. In contrast to the traditional concept of security linked to military capacity and economic power, human security represents the degree to which human beings are protected from ignorance, sickness, hunger, neglect and persecution. Until the demands for human security are met, discord will continue to boil in all regions of the world, periodically escalating into violent confrontations.*"

With the recent approval of the TASH Resolution on Peace, the Board demonstrates TASH's commitment to work for peaceful solutions to all local, national, and international hostilities and conflicts irrespective of race, creed, national origin, gender, sexual orientation, or disability. The members of the Peace Committee hope to position TASH to work collaboratively with local, national, and international communities to provide advocacy to individuals and their families who acquire disabilities as the result of war, landmines, hate crimes, acts of violence, neglect, or abuse. True to the TASH mission, we believe that TASH should take a leadership role in the international community to promote the full inclusion and participation in all aspects of life of those individuals and their families who acquire disabilities as the result of war and acts of violence.

As we look at the peace-related work being done throughout the world, we find recurring themes that are completely congruent with the organizational goals of TASH. For instance, the Hague Agenda for Peace and Justice in the 21st Century, which proposes the agenda for the United Nations, stresses that "the violation of human rights is one of the root causes of war. These violations include the denial of economic, social and cultural rights, as well as political and civil rights" (in other words, the exclusion and maginalization of segments of given communities)." Additionally "[t]hose who have suffered the most must have a place at the table when peace agreements are drawn up, with equal representation."

Obviously, this focus is not a stretch for TASH. Also not a stretch is the peace movement's focus on self-determination for those citizens who have typically been excluded: "[m]any of today's violent and persistent conflicts are between states and unrepresented people and are characterized by an extreme power imbalance. ... To counteract the power imbalance which drives these conflicts, it is necessary for the international governmental and non-governmental community to actively support peoples' right to self-determination, to prioritise these conflicts and to promote their non-violent resolution. ... It is therefore imperative that the internationally recognized right to self-determination be actively promoted as a tool of conflict prevention and conflict resolution".

TASH must continue to demonstrate its' dedication to working to assure that intolerance and discrimination and other civil rights violations associated with disability are included within all peace agendas. Simultaneously, TASH must assure that the additional impact of disability on racial, ethnic, religious, gender and sexual orientation intolerance is addressed as well. Clearly, TASH should be working to position the organization to assume a leadership role in the peace community assuring that all World Congresses and international forums address disability and that people with disabilities participate in these discussions. TASH must work with the international community to assure that

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TASH Joins with the International Community to Support Peace

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all persons who develop disabilities as the result of war and violence (many of whom do not identify themselves with the disability community) are afforded the same rights as the individuals with disabilities that TASH has historically represented. As we know "[c]hildren and youth continue to be exploited and victimized, particularly in violent conflict situations where harming children has become not only a consequence, but frequently a strategy of war" (Hague Agenda).

TASH must also work actively to eliminate violence at the local level, particularly at the community level. The Hague Agenda documents the finding that: "[v]iolence in the local communities paves the way for conflicts at the national and international levels." Many TASH members are already engaging in working to build inclusive communities where all people belong. As part of TASH's peace initiative, it will be important to make sure that this work is highlighted and focused to more actively reflect peacemaking and conflict resolution at the local level. TASH must be willing to voice a stronger presence internationally in response to the treatment of people with challenging behaviors. Positive Behavioral Support strategies must begin to be developed for including those who are currently excluded from their communities and forced to respond in acts of violence that are self-directed and/or directed towards others. The international peace movement also highlights this critical need. The Hague Agenda suggests that schools, educators, and communities must work to:

"[r]eintegrate into society the young people and some of their elders who have been marginalized, often as a result of limited economic opportunities, and whose marginalization has led them into violent behavior."

At the local-level, TASH must continue working to strengthen local communities' capacities to include all people. So much of the work of inclusion is about strengthening local capacity that this item appears to be a natural fit for TASH. Through this work we have learned that communities benefit as much as, if not more than, the individuals with disabilities.

As further described in the Hague Agenda, "[s]trengthening such 'local capacities' is vital to the maintenance of peace and may take many forms from education and training and nurturing the volunteer spirit in society, to increased funding of local peacebuilding initiatives and highlighting the work of local peacemakers in the media." TASH must continue its current work while positioning itself within the international peace community to make sure that ALL truly does means ALL.

TASH RESOLUTION ON PEACE

TASH is dedicated to upholding the dignity of life for all persons with disabilities by actively engaging in peacemaking in the world community. TASH recognizes that what may be conceptualized as being about, for, or even with people with disabilities, is more profoundly about all of us as human beings.

As an organization, TASH is working to eradicate injustices and inequities and build peaceful communities where all people belong and are nurtured to share their special gifts. TASH acknowledges that peacemaking must begin with the individual and requires that each of us must celebrate our own diversity. TASH recognizes that true compassion is authenticated in feelings of personal responsibility for the welfare, rights, and happiness of all human beings.

Because war, landmines, hate crimes, acts of violence, neglect, or abuse have increased the number of persons with disabilities in the world community;

Because there are too few international resources dedicated to ensuring that these persons receive the support required for life activities such as mobility, communication, self-care, and learning as necessary for independent living, employment and self-sufficiency;

Because TASH's organizational identity is deeply rooted in eradicating injustices and inequalities and building peaceful communities where all people are fully included;

Because TASH is committed to work for peaceful solutions to all local, national, and international hostilities and conflicts without regard to race creed, national origin, gender, sexual orientation, or disability;

Because TASH is dedicated to the dignity of life of people with disabilities, and peacemaking is deeply rooted in its organizational identity;

And because TASH's expression of peacemaking is manifested in nonviolence and compassion;

THEREFORE BE IT RESOLVED, THAT TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field is resolved and ready to work collaboratively with the world community to provide advocacy to individuals with disabilities and their families. TASH will take a leadership role in the international community to promote the full inclusion and participation in all aspects of life for those individuals who became disabled as the result of war and other acts of violence and their families.

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Systems Change and Supported Employment: Is There Empirical Evidence of Change?

BY DAVID MANK

Since 1985, the national initiative about supported employment for people with significant disabilities has been characterized, and perhaps haunted, by the phrase "systems change." Supported employment began with a small number of unique demonstration programs scattered around the USA that clearly showed that people with significant disabilities could work successfully in real jobs in typical business settings if provided individual supports for long term success. The successes of these projects created a widespread dissonance: if the individuals in these demonstration projects could succeed in integrated employment, what about the hundreds of thousands of others with similar support needs spending their days in segregated settings, largely unemployed or under employed?

Hence, led by local innovations and federal incentives, supporters and advocates of supported employment embarked on a mission to "change the system" from segregation and unemployment to integrated employment with long term supports. In the last fifteen years, more than 150,000 people with significant disabilities are working in typical business settings. Their ranks include people with intellectual disabilities, people with mental illness, people with brain injuries, and people with multiple disabilities. By some measures, and if we consider continuity in growth, supported employment is succeeding. And yet, if we consider that hundreds of thousands that continue to wait, we might conclude that the initiative remains an underachiever.

But is the system changing? Is supported employment inexorably replacing segregation, or has it simply been an interesting addition to a range of services that continues to embrace underemployment and segregation?

For the last three years, the Indiana Institute on Disability and Community has been pursuing such questions as a part of the National Supported Employment Consortium, led by the Rehabilitation Research and Training Center at Virginia Commonwealth University. This work has led to questions about how social systems change, how economic, political and cultural influences effect change, how federal and state policy and incentives influence change, and ways to consider whether or not supported employment is representing "systems change."

The body of literature about change in social services overall suggests that sustained and widespread change is more likely in states where the federal government mandates and funds the change and takes longer and is less widespread if there are no financial benefits to states. Federal leadership enhances change if there is clear policy direction and if there are incentives to change. In supported employment, we know that the federal government has provided some policy leadership and incentives to states. We also know that conflicts in policy exist and that there is no mandate of change to supported employment.

Pioneer states on social initiatives usually emerge based on state culture, industrialization, urbanization, tax rates and economic conditions. Overall, the size of disability advocacy groups and emergence of states' civil rights legislation are better predictors than state wealth of overall state investment in services for people with disabilities. Surely, supported employment is not immune to the cultural, contextual, economic and political influences.

In the last 15 years, the federal government has invested more than $100 million in systems change and related projects in 48 states. Our analysis has centered on identifying states that appear to have more widespread implementation of supported employment and to identify the context variables in those states compared to other states.

One measure of state level progress (but certainly not the only measure) is the rate on implementation. That is, what is the rate of access to supported employment per 100,000 of state population? Our analysis considered states in the top one-third on this measure, considering data available about implementation at four

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Systems Change and Supported Employment: Is There Empirical Evidence of Change?

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points in time in the late 1980's and in the 1990's. By this measure, 28 states were a part of the top third in implementation at least once. Seventeen states were a part of the top third at least twice. Ten states were consistently a part of the top third.

> ***Perhaps the greatest measure of systems change will be the extent to which supported employment continues to grow to include every person with a significant disability who wants a job in an integrated setting with long-term and personalized supports.***

Those states consistently implementing supported employment at a higher rate were more likely to have been one of the first 10 states to receive systems change incentive grants from OSERS, or states that received such incentive funding for more than five years. In addition, states with the highest rates of supported employment were more likely to have greater funding invested in supported employment relative to per capita income and higher overall employment rates. Further, those states with higher rates of supported employment have higher rates of people with mental illness in supported employment.

These kinds of results are tantalizing but hardly conclusive. The rate of implementation is but one measure. Quality of implementation, continuity in change, expansion to people with disabilities other than intellectual disabilities, are also valid measures of progress. Questions about the extent to which there is systems change must also take other factors into account:

- States have shared leadership roles in supported employment.
- State leadership in implementation has included states from varied cultural and political contexts.
- While some early state implementors led in pace of implementation, it is also clear that states without systems change grants emulated pioneer states.
- There has been continuity of growth across 15 years.
- As many as 40 states now have advocacy organizations specific to supported employment (Associations for Persons in Supported Employment).

The question often asked about supported employment is: Has the "system" changed? As we consider both the good news and the bad news about implementation, perhaps the better question is this: Is the system changing? Rather than a retrospective question, perhaps the greatest measure of systems change will be the extent to which supported employment continues to grow to include every person with a significant disability who wants a job in an integrated setting with long-term and personalized supports.

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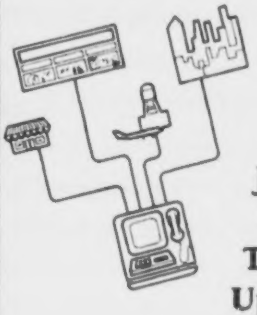
Questions regarding this article may be directed to Dr. Mank at <dmank@indiana.edu>

TASH wishes to acknowledge the generous support of our newest lifetime member

Anne C. Smith
Baltimore, Maryland

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.



Join the TASH Update E-mail Listserve!

This is a forum for TASH members, friends and supporters to discuss the latest issues affecting people with disabilities. The listserve provides members and other interested persons with an opportunity to identify and connect with others who share particular interests, expertise and experiences.

You can subscribe directly from TASH's web site at www.tash.org, or you can send an e-mail to: <TASHUpdate-subscribe@egroups.com>

THE COMMUNITY IMPERATIVE

In 1979, the Center on Human Policy at Syracuse University wrote *The Community Imperative*, a declaration supporting the right of all people with disabilities to community living. The Center has reissued *The Community Imperative* in 2000 and invites endorsements from individuals and organizations.

Background to *The Community Imperative*

The Community Imperative was written in response to organized opposition to deinstitutionalization and community living. Specifically, *The Community Imperative* was intended to counter a 1978 memorandum submitted by 10 national experts in hearings in the Wyatt case in Alabama that argued that only a small number of institutional residents could be expected to adjust to community living and that training programs were inappropriate for a substantial number of them. The purpose of *The Community Imperative* was to establish that all human beings, regardless of nature and severity of disability, are inherently valuable, have fundamental rights, and are capable of learning, growth, and development.

The Community Imperative was written by the Center on Human Policy at Syracuse University, under the leadership of the late Burton Blatt. In addition to Center on Human Policy staff and associates Ellen Barnes, Douglas Biklen, Robert Bogdan, Hillery Schneiderman, Jo Scro, Steven Taylor, and Wolf Wolfensberger, *The Community Imperative* was endorsed by over 300 parents, people with disabilities, researchers, and professionals. The initial list of signers included such leaders as: Gunnar Dybwad, Rosemary Dybwad, Robert Perske, Alan Abeson, Allan Bergman, Ed Roberts, David Braddock, Lou Brown, Allen Crocker, Seymour Sarason, Eleanor Elkin, James Ellis, Philip Roos, Frank Laski, Judy Heumann, Linda Glenn, Bruce Ennis, Marc Gold, Fred Krause, Horace Mann, Lotte Moise, Bengt Nirje, Tom Nerney, John O'Brien, Patty Smith, Edward Skarnulis, Ann Turnbull, Rud Turnbull and Jean Vanier, among others.

Why Has the Center on Human Policy Reissued The Community Imperative?

Today, 21 years after *The Community Imperative* was written, deinstitutionalization and inclusion remain controversial in some states and localities. Current debates and controversies surrounding community living obscure fundamental disagreements over values and beliefs between those who support and those who oppose inclusion. The Center on Human Policy believes that it is necessary to focus attention on the principles underlying community inclusion.

The time to debate the place of people with disabilities in the society and the community has long since passed. It is time to shift attention to assuring that community living is accomplished in a manner consistent with the values and beliefs expressed in *The Community Imperative*. The full text of *The Community Imperative* follows on page 19.

How To Endorse The Community Imperative

Individuals can endorse *The Community Imperative* by contacting the Center on Human Policy by mail (Syracuse University, 805 South Crouse Avenue, Syracuse, NY 13244-2280), fax (315-443-4338), or e-mail (thechp@sued.syr.edu). Please state your endorsement of *The Community Imperative* and provide the following information:

Name
Title (Optional)
Organizational Affiliation (Optional-for identification purposes only)
City/State/Country
Mailing Address (Optional)
E-mail (Optional)

Organizations can also endorse *The Community Imperative*. The President or Director of the organization should contact the Center on Human Policy (see contact numbers listed above). Clearly state that you are endorsing *The Community Imperative* on the behalf of your organization and provide the following information:

Name of Organization
City/State/Country
Mailing Address (Optional)
E-mail (Optional)

A listing of individuals who endorsed *The Community Imperative* in 1979 can be viewed at: http://soeweb.syr.edu/thechp/initial_list.html

A current list of individual endorsements of *The Community Imperative* can be viewed at: http://soeweb.syr.edu/thechp/individual_endorsements.html

A current list of organizational endorsements of *The Community Imperative* can be viewed at: http://soeweb.syr.edu/thechp/organization_endorsements.html

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Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred. The Center on Human Policy subcontracts with TASH for space in this newsletter.

The Community Imperative:

A Refutation of All Arguments in Support of Institutionalizing Anybody Because of Mental Retardation[1]

In the domain of Human Rights:

❖All people have fundamental moral and constitutional rights.
❖These rights must not be abrogated merely because a person has a mental or physical disability.
❖Among these fundamental rights is the right to community living.

In the domain of Educational Programming and Human Services:

❖All people, as human beings, are inherently valuable.
❖All people can grow and develop.
❖All people are entitled to conditions which foster their development.
❖Such conditions are optimally provided in community settings.

Therefore:

In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.

[1] A more accessible version of this statement, developed by self-advocates in March 2000, is available, and can be viewed at the Center on Human Policy's web site: http://soeweb.syr.edu/thechp/community_statement.html

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Excerpts from 1999 TASH Annual Conference Keynote Address by Diane Coleman

It's an honor to be invited to speak to some of the toughest in-the-trenches advocates ever known about the growing threat of the euthanasia movement, to not only our core civil rights principles but our very lives. As we work on day-to-day battles enforcing our hard won civil rights, we may be at risk of losing the war. If we're not careful we may be taken by surprise.

I first became involved in the assisted suicide issue in 1985. I was a lawyer in Los Angeles serving on the Board of the Disabilities Rights Organization and I got a call asking me to spend my lunch hour at a rally. It was about a 26-year-old woman with cerebral palsy named Elizabeth. At the age of 10, she had been put in an institution but she had gotten out. She used a wheelchair. She went to college. She got married. She was going to have a baby but then she had a miscarriage. In a short time, her marriage broke up. Her brother died in a drowning accident. Her mother got cancer. So she went to a hospital and she wanted help to starve herself to death. The hospital refused, but a lawyer took her case. He was the co-founder of the National Hemlock Society and he found a psychologist to say that Elizabeth's desire to die was based on her suffering from her cerebral palsy rather than any temporary despair caused by her recent traumas.

We held a disability rights rally to protest. No one would want to help Elizabeth commit suicide if she were nondisabled. But no one listened to us. The press was all over it — the same press that doesn't cover our struggle for freedom and civil rights — the same press that tells us we have no dignity if we need personal assistance. Elizabeth said she wanted to die to have dignity and that was news. The court found that she should have a so-called "right to die," but the case had taken a couple of years. So, by then she didn't do it and she's still alive.

Under the assisted suicide bill currently pending in New Hampshire, which applies to almost everyone with an incurable condition, not just terminal, Elizabeth would have been eligible for doctor-assisted, guaranteed successful suicide and she would have had only a two week waiting period, not two years, to get over it and change her mind or she would be dead. Until recently, the most public face of the euthanasia movement has focused on assisted-suicide for people who are terminally ill and who are conscious, deemed competent and appear to make a voluntary choice. I usually spend most of my speeches talking about how it's about disability too, not just terminal illness and how it isn't very voluntary if society won't pay for your personal assistance, your transportation or your education. But, more and more lately, non-voluntary euthanasia is becoming an open topic of discussion, I should say an open topic again. Let me offer a little history.

In 1942, Foster Kennedy wrote an article in the American Journal of Psychiatry entitled *"The Problem of Social Control of the Congenital Defective, Education, Sterilization, Euthanasia."* He said "I believe that when the defective child shall have reached the age of five years and a competent medical board on the applications of the guardians of the child and after three examinations should decide that the defective has no future or hope of one, then I believe it is a merciful and kindly thing to relieve that defective, often tortured and convulsed, grotesque and absurd, useless and foolish and entirely undesirable of the agony of living."

Kennedy was not proposing anything new or shocking. In fact, his article was focused on just what part of the Nazi CT4 program should be adopted in the United States. T4 was the code name for the extermination program of people with disabilities under the Nazis. It's also no accident that the activities of the Third Reich and Kennedy's recommendations were in agreement. The United States had mandatory sterilization laws on the books in over 25 states before Germany, and the same influential professionals and reformers pushing those laws were already discussing the feasibility of a mercy killing protocol and how it should be implemented. While the United States condemned other activities of the Nazi killing machine, American prosecutors and judges at Nuremburg failed to label the killing of disabled people as crimes against humanity.

In 1989, the U.S. Civil Commission issued a 153 page report entitled Medical Discrimination Against Children With Disabilities. Among the information considered by the Commission in reaching its findings was an experiment conducted from 1977 to 1982 by four doctors and a social worker at the Children's Hospital of Oklahoma. The doctors developed a quality of life formula which took into account the natural endowment of babies with spina bifida, as well as the socio-economic status of the babies' families. The doctors used the quality of life formula to determine which families they would advise to provide a relatively simple life-saving medical procedure and which families they would advise to let the baby die. Without being told they were part of a study, better-off families were provided a realistic and optimistic prognosis of their child's potential, while poor families

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were provided a pessimistic picture. Four out of five poor families accepted the doctors' advice and 24 babies lost their lives.

In 1990 the U.S. Supreme Court broadly expanded the conditions under which life could be terminated through the denial of medical treatment, and the law has continued to evolve through both state legislatures and the courts. Right now, in California, an appellate case is pending involving a man with head injuries who can't speak but understands and responds to simple requests and moves about in his motorized wheelchair. Robert Wenlend was placed on a feeding tube due to swallowing difficulties. For the last few years his wife has been opposing rehabilitation and trying to get the feeding tube withdrawn to kill him. The man's mother and sister oppose the wife which is why the case is in court. The lower court judge told the wife that he was sorry but, Wenland was not in a coma and California's legal standards for a family member to stop a feeding tube were not met. The wife was trying to push the legal envelope. She says even if her husband was able to clearly articulate his wish to live, that she should be allowed to kill him because as far as she was concerned, he died in the accident. Her attorney says Robert Wenland's responses are nothing but those of a trained animal.

> **The idea that people with disabilities are not worthy of society's acceptance or resources is not new. But for the first time in history, people with disabilities are organizing our community to fight back to demand the equal protection of the law.**

Policies are also evolving in hospitals. With the support and guidance of the American Medical Association, many individual hospitals are developing and expanding guidelines which allow doctors to withhold treatment against the express wishes of a patient or their family. Tracy Lattimore was 12 years old. She had severe cerebral palsy and was unable to speak. She was known to be able to enjoy activities and friends in spite of chronic pain that she experienced in her hip. In 1993, Robert Lattimore, a farmer in Canada, stayed home with his daughter, Tracy, while the rest of the family went to church. He carried Tracy to the barn, put her in the front seat of his truck, started the truck, piped the exhaust into the cab, closed the barn doors and left her there. Once she was dead, he carried her body back to the house and put the body in bed. He informed the family and authorities that she had apparently died in bed. Fortunately, the coroner was somewhat suspicious and performed an autopsy. Once confronted with the evidence, Robert Lattimore confessed to the murder. He claims to have killed Tracy for her own good.

Almost immediately the press seemed to embrace Lattimore's sincerity and his assertion that the killing was an act of love. Robert Lattimore's first trial resulted in a conviction for second degree murder which carries a mandatory 10 year sentence in Canada before parole can even be considered. This resulted in a loud public outcry that this was too extreme a sentence. Due to possible improper behavior by authorities in questioning perspective jurors in the first trial, Robert Lattimore's conviction was overthrown. Fortunately, there was a second trial and the jury rendered the same verdict, but the sentence has been appealed again and he is still free.

What a contrast to the Susan Smith case here in the United States. It's important for people to know the role that pro-assisted suicide groups have played in this case. In Canada, they openly support Lattimore. One of the founders of the group Dying With Dignity has been quoted in the press as calling disability activists meddlers and saying that the family has suffered enough. Another person was quoted in a 1994 New York Times article as asserting that Lattimore's original sentence was unconscionable since Lattimore and his wife had already served a sentence of 12 years, the length of Tracy's life. The press never asked what does Tracy's death have to do with voluntary assisted suicide — the supposed purpose of the organization. Two years ago, on December 3, 1997, the Hemlock Society USA issued a press release in regard to mercy killing and non-voluntary euthanasia. Hemlock has been the most influential lobbying organization for assisted suicide in the U.S. In the release, Hemlock director Faye Gersh said that alleged mercy killing should be treated as special crimes of compassion and evaluated separately. She also said that families should be able to obtain a court-approved euthanasia of a demented parent, a suffering, severely disabled spouse or a child if that life is too burdensome to continue.

In his latest book, Derrick Humphrey, the Hemlock Society co-founder, best known for his earlier book Final Exit, wrote: "The right to die is but one element of a larger set of medical, cultural, legal and economic issues that have converged in response to the extraordinary capability of medical technology to extend life. In attempting to answer the question 'why,' one must look at the realities of the increasing costs of healthcare in an aging society because, in the final analysis, economics, not the quest for broadened individual liberties or increased autonomy, will drive assisted suicide to the plateau of acceptable practice — a duty to die." Now all we need is an ethical justification to back up economic and compassion arguments.

The chair of the National Bioethics Advisory Commission is the president of Princeton University. He spent the last

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Excerpts from 1999 Conference Keynote Address by Diane Coleman

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decade recruiting someone to fill a chair in bioethics funded by the Ira W. D'Camp Foundation. This year Princeton hired Peter Singer. This semester Singer is teaching from his book Practical Ethics and Rethinking Life and Death. According to Singer, to be ethical we must treat all persons according to moral guidelines, but not all human beings are persons. Singer claims that in order to be persons and to deserve moral consideration, beings must be self-aware and capable of perceiving themselves as individuals through time. Singer claims that no newborn infants are persons. He claims that some people with lifelong cognitive disabilities never become persons at any time throughout their lives and he claims that some people who acquire cognitive disabilities through injury, Alzheimer's disease or other means, cease to be persons. It may be all right according to Singer to kill infants. Singer is quick to note that it is still illegal to kill most infants for other reasons. But, infants with known disabilities, especially cognitive disabilities, he says, do not bring the same amount of happiness into the lives of their parents. Additionally, the very fact that some people are disabled means that they will have unhappier lives than other people and, therefore, the reasons not to kill non-disabled infants do not apply to disabled infants. Singer suggests that it should be legal for parents to decide to have their disabled infants killed up to 28 days after birth. This way, he says, parents could have non-disabled replacements. In addition, the infants would provide a source of organs for transportation to other infants who could grow up to be non-disabled. It may also be all right according to Singer to kill people whose doctors claim they are severely cognitively disabled.

Although Singer doesn't give a list, we know that people with labels such as mentally retarded, demented, persistent vegetative state and severely brain damaged are likely to have that judgement applied to them. Singer claims that some people with these labels are not persons. The euthanasia of people whose minds are judged inadequate would be a way to save money. It would be a way to allow families to move on and it would provide a source of organs for transportation to people whose minds are judged to be acceptable.

According to Singer, very often people with cognitive disabilities should be killed. In the popular press such as in New Yorker magazine or Newsweek, Singer claims that all he's doing is openly talking about what most people think. Considering everything we go through to secure our rights on a day-to-day basis, we should not really be shocked and we should certainly not think that the press and the public will resist Singer's influence on bioethics or on public policy, nor should we think that our political friends in the civil rights and social justice communities will easily come forward in our defense. In fact, these friends have been swayed by a lazy and biased press into thinking that euthanasia is a progressive social cause.

Last week I spoke about home and community-based services and Olmstead at a universal healthcare conference, while in a concurrent session a woman supported euthanasia in the same breath as reproductive rights. If we do not educate and advocate against a legalized duty to die, if we allow ourselves to be broadsided by the euthanasia movement, then in the words of Norm Kunc on this issue, we will be building snowmen when an avalanche is coming.

In terms of advocacy I have a few good things to report. Last month, Paul Marchand, on behalf of the Consortium for Citizens With Disabilities, sent a letter to the president of Princeton University. In it he said CCD joins Not Dead Yet, Justice for All and many other groups in conveying the view that the dangerous and barbaric views of Peter Singer regarding infants with disabilities has absolutely no place in American society or academia. Taken in or out of context, Dr. Singer's position and writings regarding the value of lives of people with disabilities are outrageous. They are bigoted, hateful and fly in the face of everything our society and our national policy speaks for its constituencies. So far, the following national disability rights organizations have joined Not Dead Yet in opposing the legalization of assisted suicide and euthanasia: The National Council on Independent Living, The Council on Disabilities, ADAPT, Justice for All, TASH, The National Spinal Cord Injury Association, The World Association of Persons With Disabilities, The World Institute on Disabilities and, I am happy to hear for the first time announced, the addition of our 10th national organization, The Disability Rights Education and Defense Fund.

> *The euthanasia movement is a worldwide political movement with an agenda that includes the killing of people with disabilities, young and old, terminal and non-terminal, adults and infants, voluntary and non-voluntary.*

In *Credo for Support,* Norm Kunc and Emma Vandercliff remind us that throughout history people with physical and mental disabilities have been abandoned at birth, banished from society, used as court justers, drowned and burned during the inquisitions, gassed in Nazi Germany and still continue to be segregated, institutionalized, tortured in the name of behavior management, abused, raped, euthanized and murdered. The euthanasia movement is a worldwide political movement with an

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Excerpts from 1999 Conference Keynote Address by Diane Coleman

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agenda that includes the killing of people with disabilities, young and old, terminal and non-terminal, adults and infants, voluntary and non-voluntary.

The idea that people with disabilities are not worthy of society's acceptance or resources is not new. We see this form of hatred throughout history often masked as benevolent. But, for the first time in history, people with disabilities are organizing our community to fight back to demand the equal protection of the law. Our expression of this demand put Jack Kervorkian in jail. But the greater fight lies ahead in the next millennium. People with disabilities have an opportunity to lead society from the isolation and despair of today into a recognition of belonging, interdependency and community for all. Please come to the Not Dead yet workshop Saturday. Visit us at our booth. Find out what you can do to help support and join us in the fight for our lives before it's too late. Thank you.

Diane Coleman has worked as an organizer for ADAPT and founded Not Dead Yet, a national grassroots disability rights organization leading the disability community's opposition to the legislation of assisted suicide and euthanasia.

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

A DREAM IS REALIZED

The World Congress & Exposition on Disabilities (WCD), a precedent-setting international conference and trade show three years in the making, will take place at the Georgia International Convention Center in Atlanta, November 10-12, 2000. The WCD is intended to educate, inform and provide a useful exchange of ideas for people with disabilities and special healthcare needs and those involved in their care and development. Opinion leaders in medicine, education, research, technology and product development will gather along with caregivers and families for an intensive learning experience focused on the needs of all people with disabilities.

Seminars on three tracks (Track 1 is designed for physicians, OTs, PTs, SLPs; Track 2 is for the education community; and Track 3 is designed for direct support professionals, families, caregivers and people with disabilities) are being planned to best serve the show's expected 8-10,000 attendees. The entire curriculum has been developed by a Steering Committee made up of leaders in medicine, science, the government, the private sector, non-profit organizations and associations, educators and families, and is being produced under the auspices of the EP Foundation for Education, Inc., a 501(c)(3) non-profit organization.

In addition to the conference program, the event will provide an opportunity to examine the latest products and services from hundreds of exhibitors. The conference will also feature a career fair, as well as a number of Activity Centers, designed as interactive, educational and fun.

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The Serena Merck Memorial Award

For Innovation and Dedication in Practice

Purpose of the Award The Serena Merck Memorial Award is given annually to an exceptional individual who has demonstrated long-term, selfless dedication and compassion in the care or service to children who have retardation and significant mental health problems. Mrs. Merck recognized the critical importance of what quality day-to-day care provided by committed individuals can make to children with cognitive and behavioral disabilities. The John Merck Fund has established this major, national award to honor her long-standing commitment to this field, and to call attention to the invaluable role caring individuals play in it.

Criteria for Selection of the Awardee Prospective awardees should meet one of the following categories: (1) Provides, as an employee or volunteer, services for children who have mental retardation and significant mental health problems. (2) Demonstrates long-standing commitment and innovative care of this population which has positively affected their quality of life and/or life opportunities.

Submission Guidelines Organizational entities may nominate prospective awardees. One nomination per organization is permitted, although multi-service organizations may submit one nomination from more than one service unit. No self-nominations are acceptable. Only organizations serving children with mental retardation and significant mental health problems are eligible to nominate an individual. A 500-word summary of the reason the candidate is nominated, length of service in the field, and a description of the person's impact on children with mental retardation and significant mental health problems is required. At least two, but no more than five, accompanying letters of reference from individuals well qualified to evaluate the candidate's suitability for the award should be provided.

Nominations should be mailed before September 15, 2000 to:
Mr. Frank Hatch, The John Merck Fund, 11 Beacon Street, Suite 1230, Boston, MA 02108

Award A $5,000 cash award and plaque will be presented to the awardee at the 17th Annual National Association for the Dually Diagnosed (NADD) Conference held November 1-4, 2000, in San Francisco, California. The awardee's travel expenses to the conference will also be covered.

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TASH has a Student Membership Program!

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An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

Cost Effectiveness of Supported Employment Programs:

What We Need to Do to Improve Outcomes

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BY GRANT REVELL, JOHN KREGEL, AND PAUL WEHMAN

Supported employment is one program specifically designed to assist persons with the most significant disabilities to achieve competitive level, community integrated employment. Supported employment first received public funding thought the Rehabilitation Act Amendments of 1986. It has enjoyed steadily increasing popularity since its inception and has achieved carefully documented positive outcomes (Mank, O'Neill, & Jensen, in press; Revell, Wehman, Kregel, West, & Rayfield, 1994).

The major premise of a supported employment program is that many persons with significant disabilities need some additional support at the jobsite in order to work successfully. Through the use of employment specialists, mentors, co-workers and employers, the impediments to employment faced by prospective workers are reduced, and their abilities and work potentials are emphasized through supports designed at the workplace. Despite the demonstrated success and value of this model and research that confirms its efficacy (e.g., Bond, Dietzen, McGrew, & Miller, 1995; Drake, McHugo, Becker, Anthony, & Clark, 1996; Coker, Osgood, & Clouse, 1995), supported employment has not yet been fully utilized to impact the thousands of people with disabilities who remain unemployed.

One area which has not been studied closely enough in supported employment has been the cost effectiveness of the program. Supported employment has shown that it is cost-efficient in comparison to alternative programs models, such as sheltered employment for person with developmental disabilities and rehabilitative day treatment programs for persons with significant mental illness (Cimera & Rusch, 1999; Clark et al, 1996). However, we propose to take a closer look at recommendations for promoting more cost effectiveness in supported employment.

This section presents further information on the size and outcomes of the supported employment program by providing FY 1995 data collected from state rehabilitation and other state level agencies funding supported employment services in each of the 50 states in the country.

Cost-Effectiveness of Supported Employment Related to Meaningful Employment Outcomes

The assessment of cost-effectiveness of supported employment programs can best be understood in the context of systematic assessment of (1) program services, (2) case mix, and (3) vocational outcomes. Regarding program services, many providers offering supported employment fail to provide services that exemplify the critical ingredients of supported employment. Bond (1999) has developed an instrument, known as the Quality of Supported Employment Implementation Scale (QSEIS), which assesses programs on 33 behavioral indicators via a brief interview. Indicators include intensity of service, length of follow-up, rapid job search procedures, integration of vocational and treatment services, and placements based on consumer preferences and needs. Interviews have been completed with 42 providers in 3 states. The variation in ratings on this scale suggest unequal implementation along quality dimensions, which in turn may relate to program effectiveness and serve as an upper bound on cost effectiveness. A program that is not effective in helping people obtain employment cannot be cost effective.

Regarding case mix, it is clear that costs vary widely according to intensity of services provided, which in turn is likely to vary widely as a function of severity of disability. Our research continues to seek the best indicators of case mix.

With regard to vocational outcomes, we have found that different outcome measures are not always highly correlated. If the vocational rehabilitation (VR) closure rate is used as the primary indicator of performance, then it will not necessarily lead to desired job tenure outcomes. In our pilot research, those programs that emphasize vocational planning and long-term support had better job tenure. However, these same programs did not have the highest VR closure rates. In other words, choice of employment outcome indicators is a critical decision that impacts the evaluation of a program's cost-effectiveness. (Bond et al, 1999).

Future direction needed for this research is to inquire into the validity of the QSEIS and employment indicators to better understand what services are effective, with which clients, and for which outcomes. Validation requires a

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sufficiently large data base to obtain interpretable patterns of relationships. Cost effectiveness can than be tied to these indicators. The SEC has been sampling in widely diverse service settings to enhance the external validity of this methodology. Research can adapt this instrument for use as a checklist that can be used by family members and consumers for making informed decisions about services, especially as we move toward voucher systems in which consumers have a choice among providers. The Quality of Supported Employment Implementation Scale (QSEIS) can be a highly useful tool to quantitatively connect quality supported employment outcomes with cost effectiveness.

Cost-Effectiveness of Supported Employment Related to How Funding Agencies Purchase Services

It is essential to ground a discussion of cost effectiveness related to funding methodologies in the day-to-day realities faced by state agencies, providers, and individual job coaches working with funding and cost issues. For example, consider this issue at the job coach level. Inge (1999) has recently run a Web-based course on supported employment. This course was targeted to direct service staff. Students were recently asked to post questions on funding difficulties they are experiencing related to persons with the most significant disabilities. Here are two representative postings:

> *Program improvements are needed in supported employment that fairly match costs to outcomes, leading directly to funding designs that balance the desire of funding agencies for cost efficiencies and the need of persons with the most significant disabilities for quality services and supports.*

(1) My experience has been that our VR agency feels that persons with significant disabilities and persons with developmental disabilities are a risk to open eligibility on. The VR program is so tied to outcomes of closures of success that there is a resistance to eligibility.

(2) Probably the biggest obstacle that we have come up against in getting funding for individuals with significant disabilities is getting vocational rehabilitation funding. VR funding is so limited that most of the monies available go to more readily employable people. VR agencies seem to be in a pinch of sorts and are more willing to help the people who are ready to go to work right away with little accommodations. These responses point directly to the ongoing struggle of VR to effectively allot resources to services for persons with the most significant disabilities. Funding designs are needed that match efficient use of funds to securing competitive employment outcomes for persons with the most significant disabilities.

One must also review this issue at the provider level. A provider agency asked recently for help in evaluating a results-based, fixed price funding contract proposal being offered by a local (non-VR) funding agency. The provider was concerned that the proposed outcomes payments would not cover the true cost of services required by the population. Subsequently, it was determined that the contract did under-fund the necessary services. The funding agency pushed cost efficiency (controlling costs) at the expense of effectiveness (quality of SE outcome). If the provider entered into the contract, covering costs would mean the staff of this agency would have to "cream" (only provide services to those individuals who required the least supports) its referral pool and/or cut back on service quality, usually resulting in poorer quality job matches and tenuous job security. The provider rejected this funding proposal. Program improvements are needed in supported employment that fairly match costs to outcomes, leading directly to funding designs that balance the desire of funding agencies for cost efficiencies and the need of persons with the most significant disabilities for quality services and supports.

Here is a final example, one that occurs at the state level: Last fiscal year, a state vocational rehabilitation agency had a severe fiscal crisis. The agency, with minimal lead time, implemented a results-based funding design for supported employment that replaced an hourly fee program. The supported employment state VR program manager asked consultants to help review the recently implemented new system and to point out possible improvements. State VR agencies are aggressively seeking to redesign funding methods for supported employment. The efficacy and impact of these designs need evaluation. A trial and error approach to these funding methodologies will only compound the documented difficulties VR is already experiencing in providing supported employment services to persons with the most significant disabilities in a cost efficient and effective manner.

Preliminary Findings on Key Characteristics of Successful Funding Designs

Results-based funding designs are being implemented that clearly identify the desired employment outcome, define the quality indicators that substantiate the achievement of those outcomes, and establish a payment schedule specific to outcomes achieved. Research completed to date on achieving a balance between cost efficiency and effectiveness in the funding of supported employment services points directly to the importance of five specific characteristics of successful funding designs (Novak et al, 1999). These five areas are assuring collabora-

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tion by key stakeholders, setting payments that truly cover the cost of services, tying payments to valued outcomes, emphasis on participant choice and self-determination, and avoiding disincentives that discourage access to SE for persons who face the most significant employment challenges. These characteristics are described in Table 1, below.

Table 1: Critical Characteristics of Successful Results Based Funding Designs

Balance the interests of key stakeholders through collaboration: The challenge is to balance the interest of outcomes at a reasonable cost. Case studies in Alabama and Oklahoma point directly to the critical importance of early involvement by all stakeholders.

Insure that funding levels are workable for providers of service. Attention is needed to the spacing and weighting of payment points, inclusion of proactive assessment job planning stategies, including in payments costs associated with participants who fail to reach key benchmarks, replacement of participants who lose jobs or seek career-oriented job changes.

Tie payments to the achievement of valued performance measures: Focus on increasing the number of people who have quality jobs by defining outcome-oriented performance measures (i.e.: degree of employer and consumer satisfactin, employment retention, wages and benefits).

Emphasize individualization, flexibility and choice: Support responsiveness to the individual participant by evaluating achieved work outcome against identified job interest, acceptable geographic location, wage and benefit reuirements, and work schedule.

Avoid creating disincentives to serving people with the most significant disabilities: Utilize options such as tiered payment levels or incentive payments that help assure access to services by the more highly challenged.

States such as Massachusetts and Oklahoma have developed results-based funding programs. The Community Based Employment Services (CBES) system used in Massachusetts (MA) and the Milestones system used in Oklahoma (OK) take substantially different approaches in key areas such as use of fixed (MA) versus negotiated (OK) rates, definition of key intermediate outcomes, and incorporation of incentives to encourage services to frequently unserved and underserved populations. However, both Community Based Employment Services (CBES) and Milestones are firmly grounded in the five principles presented below and both have documented success in improving the cost effectiveness of supported employment services from the perspective of a funding agency (O'Brien & Cook, 1998; Massachusetts Rehabilitation Commission, 1998). Impact evaluations of the Oklahoma Milestones program document improved cost efficiencies with no loss in effectiveness as measured by participation of the most highly challenged population, reduced waiting lists, reduced time to employment for persons in job development, and increased numbers of successful supported employment outcomes. The evaluation of the impact of the Massachusetts CBES program reported the following results:

- High consumer satisfaction with the model of service delivery
- Potential for flexibility and customization of services
- Reimbursement based on performance outcomes
- Increased numbers of consumers enrolled in this model of service delivery
- Inter-agency collaboration, including cost-sharing of services
- High levels of communication between provider and state agencies
- Provider and state agency satisfaction with component structure
- Provider and state agency satisfaction with rate structure

The inter-agency collaboration referred to in the CBES results summary includes shared funding for coverage of extended employment services following completion of VR funded time-limited services. Both OK and MA, using different approaches to results based funding, have successfully matched payment schedules to participant outcomes in a manner viewed by the funding agencies as cost effective. Clearly, the accomplishments reported by both Massachusetts and Oklahoma reflect the type of cost effectiveness improvements sought by RSA, VR, and other SE funding agencies.

How then can vocational rehabilitation promote improvements in the cost effectiveness of the supported employment program in terms of the quality of employment outcomes in relation to the costs to achieve these outcomes? The keys to improving cost effectiveness are found in two areas. First is the purchase of service relationship between VR and its provider agencies from whom it secures supported employment services. The second area is the collaborative relationship between VR and funding

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sources for extended supported employment services. Future efforts to improve cost effectiveness of the field application of supported employment should be targeted specifically to these two primary areas.

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TASH RESOLUTION ON PEACE

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Further, TASH is resolved to facilitate supported-community peacemaking and to build inclusive and diverse communities where all are valued.

Adopted March 2000

Craig A. Michaels, Ph.D., works at Queens College, City University of New York and is Chairperson of the TASH Peace Committee.

TASH members interested in joining the Peace Committee or finding out more about the Committee's work may contact Craig Michaels via e-mail at <cmichaels@ncds.org>

REPORT ON THE PRELIMINARY FINDINGS OF THE NATIONAL SUPPORTED EMPLOYMENT CONSORTIUM STUDY

BY GRANT REVELL

The National Supported Employment Consortium Project (SEC) for the competitive employment of people with significant disabilities is midway through its third year. The SEC is a research and technical assistance effort funded by the Rehabilitation Services Administration and administered by the Virginia Commonwealth University Rehabilitation Research and Training Center on Work Place Supports. Consortium members include the Indiana University Institute on Disability and Community, the Boston Children's Hospital Institute for Community Inclusion, Transcen Incorporated, the University of Montana Rural Institute on Disabilities, and a number of national experts including Gary Bond at Indiana University Purdue University Inidianapolis.

The SEC is conducting research in a number of areas critical to the growth and effectiveness of supported employment. Areas of research include: statewide systems change; extended supported employment services; cost effectiveness; meaningful employment outcomes; natural supports; employer impact; use of personal assistance services at the work place; and strategies to provide competitive employment opportunities to unserved and underserved populations. The SEC is actively disseminating both the results of the research studies and information on exemplary practices.

Over the last year, the SEC has conducted a series of national training sessions and published a variety of newsletters on best practices, sponsored a Summer Institute where direct service staff received 5 days of intensive training, initiated a web-based certificate course that provides interactive training on supported employment, worked hand-in-hand with rural communities to develop supported employment opportunities, co-sponsored forums on conversion and self-employment, and provided a wide variety of prescriptive technical assistance that matched national experts to state and community level requests for assistance.

The SEC recently published a research monograph titled *"The Impact of Supported Employment for People with Significant Disabilities: Preliminary Findings from the National Supported Employment Consortium."* The fifteen papers contained in this monograph reflect the breadth and depth of the SEC's evaluation activities and its intent to frame results in a practical, best practice oriented viewpoint. The papers in the monograph address supported employment issues and practices in four areas.

First, in the area of current trends and future directions, Paul Wehman and John Bricout identify and analyze the full range of employment supports needed by persons with the most significant disabilities. Jeanne Novak, David Mank, Grant Revell and Dan O'Brien describe the national trend towards more results based funding of supported employment, and provide numerous recommendations for agencies considering this funding approach. Valerie Brooke and her co-authors describe the implementation of a results based funding design in Alabama that incorporated intensive in-service training on quality supported employment services.

In the area of improving state level implementation, Martha McGaughey and David Mank analyze the evidence of systems change in supported employment to date and the factors influencing that change. Gary Bond and his research team describe the initial results of their research efforts targeted at designing a quality of supported employment implementation scale that will help generate more meaningful employment outcomes. Susan Foley and her co-authors evaluate state-level interagency collaborative efforts in supported employment with a focus on exemplary practices.

In the area of evaluating policy initiatives influencing supported employment, Martha McGaughey and David Mank describe the policy framework within which systems change takes place, and Jeanne Novak and her co-authors identify the many public initiatives currently taking place nationally influencing the move to more results based funding designs.

Finally, in the critical area of improving supported employment services and outcomes, Katherine Inge and her co-authors evaluate the results of a demonstration project that assisted individuals with very significant physical disabilities to secure work competitively. They also provide a number of best practice recommendations. Ed Turner and his co-authors provide insight into the challenges faced in securing and self-directing Personal Assistance Services at the work site for persons who need this support to work competitively. Cary Griffin evaluates the factors influencing the provision of supported employment in rural areas and provides numerous best practice recommendations for improving the quality and effectiveness of these services. Darlene Unger reports on the results of research on how employers view workplace supports. Pat Rogan and her co-authors describe a qualitative research effort to evaluate workplace supports in practice with emphasis on maximizing supports available at the job site.

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Report on the Preliminary Findings of the National Supported Employment Consortium Study

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Paul Wehman and John Bricout conclude the monograph by discussing the blending of practices identified as natural supports into a workplace supports model of supported employment services.

This first monograph published by the National Supported Employment Consortium describes the initial set of results from a wide variety of evaluation studies that are works in progress. The monograph's range of authors and topics reflect the comprehensive nature of the SEC evaluation effort. The SEC is designed to provide a steady flow of information on critical issues and best practices, and future dissemination efforts will continue to use a variety of written, web-based, and face-to-face methods to assure wide dissemination of information on SEC evaluation efforts.

Additional information about the monograph and other SEC activities may be obtained from Grant Revell, SEC Project Director, by calling (804) 828-6989 or you may send an e-mail to wgrevell@saturn.vcu.edu

Grant Revell is Project Director of the National Supported Employment Consortium, a project funded by the Rehabilitation Services Administration to identify and disseminate information on the best practices in supported employment.

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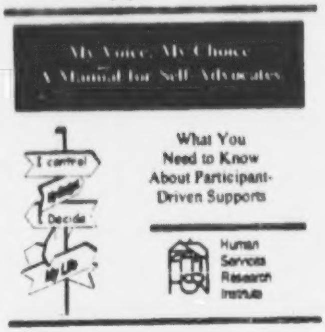
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Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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Please Check Appropriate Categories (not more than three):

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( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Advocate/Friend
( ) Behavioral Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator/Teacher (K-12)
( ) Government Personnel
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional/Public Policy Advocate
( ) Professor/Instructor-College/University
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
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( ) Student
( ) Supported Employment
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Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

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Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information in the next column:

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Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone:410/828-8274 Fax: 410/828-6706

*These prices are for both International and Chapter memberships. For International-Only or Chapter-Only rates, please call us at 1-800-482-8274.

TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204
Phone: 410/828-8274,
FAX: 410/828-6706,
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TASH Newsletter

VOLUME 26 ISSUE NUMBER 8 AUGUST 2000

The Victimization of People with Developmental Disabilities in the Criminal Justice System

INSIDE: Victims and Offenders with Mental Retardation, Trauma and People with Cognitive Disabilities, Violence Against Women with Developmental Disabilities, and Law Enforcement Awareness of Autism

Also: Remembering Marsha Forest and Highlights from the First International Self-Determination and Individualized Funding Conference

URGENT! Dated Material Inside! 2000 TASH Board Election Ballot!

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

TASH wishes to acknowledge the generous support of our newest lifetime members

Alicia A. Cone - Nashville, Tennessee
Elissa R. Theilen - Roslyn, New York

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.

Whom Do I Contact??

☐ **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org

☐ **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org

☐ **For questions about the 2000 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org

☐ **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org

☐ **For information on governmental affairs, call:** Dan Dotson, Coordinator of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:ddotson@tash.org

☐ **For information on marketing and promotions, permission and reprints, or newsletter submissions and advertising, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org

☐ **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu

☐ **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

From the Executive Director
BY NANCY WEISS

2000 TASH BOARD ELECTION

It's election time again .... not only for the presidency of the United States but for TASH's own Executive Board, as well. The Executive Board is a group of TASH members elected by you, the members, to set policy, oversee the organization's finances, and guide TASH's overall direction and goals. There is likely no more important decision an organization makes than the people it selects to guide its future.

Because we value broad participation in the TASH electoral process, this year we are offering for the first time a range of ways for members to vote. We are trying this as an experiment. If offering these various ways to vote results in broader participation in the election, we will continue it in future years.

This year there are four ways to vote: by mail, fax, e-mail, or via our web site. A Ballot Control Number has been printed on each ballot form included in this *Newsletter* (p. 9). These numbers were applied by the printing company and we have no way of matching this number with your name or member ID. This number is used to assure that each member votes only once and that your vote remains anonymous.

Here are the four ways to vote this year:

✓ On pages 4-10 of this issue of the *Newsletter* you will find candidate statements and photos, as well as a ballot form. You may vote by returning the ballot form by mail — the return postage is paid by TASH — using the self-mailer or in your own envelope, if you prefer.

✓ Your ballot form can also be returned by fax to: 410-828-6706.

✓ The complete ballot, including candidate's statements and photos, also appears on TASH's web site: www.tash.org. Look for the "Board Election 2000" button. All TASH members can vote via the web site by entering the Ballot Control Number from the ballot form on page 9 of this *Newsletter.*

✓ Finally, each TASH member for whom we have a valid e-mail address will receive an e-mail inviting them to vote by return e-mail. Even if you do not receive an e-mail from us (meaning that we do not have your correct e-mail address!), you can vote by e-mail by sending a message, no later than October 10, 2000, to ballot@tash.org. Remember that you will need to include your Ballot Control Number from the ballot form on page 9 of this *Newsletter* and that any replies containing votes for more than five candidates will not be able to be included in the final count.

We hope that these voting options will make it easier for all TASH members to participate in this year's elections. We're aiming for as inclusive a process as possible! Please call if you have any questions about voting. The five candidates who are selected will be announced in the November *Newsletter*. We appreciate your participation!

All completed ballots must be received in the TASH Central Office by October 10, 2000.

New DATE

MARCH FOR JUSTICE

We're Voting for Our Lives!

Tuesday, October 3, 2000, 12:00 Noon
U.S. Capitol grounds at Upper Senate Park (north side of the Capitol)
Washington, D.C.

The date has changed, but not the need for your support and participation! Join thousands of civil rights advocates for a rally to support the Americans with Disabilities Act (ADA). This Fall the United States Supreme Court will hear arguments in the case of Garrett v. University of Alabama, which calls into question the constitutionality of the ADA. The civil rights of millions of people with disabilities hang in the balance while we await the decision.

This is not just a case about disability rights -- it is about everyone's civil rights. There are no guarantees in life and anyone may find him/herself facing the injustice of discrimination by an employer; lack of access because of a disability; or even a serious illness such as cancer, asthma, or HIV/AIDS. Without the protections that the ADA provides to guard against injustices in the workplace and community, everyone in America is faced with the threat of losing their civil rights.

Make plans now to come to Washington, D.C. on the first Tuesday in October to join other advocates for justice and with our combined voices, we will send a loud and clear message to our elected officials and candidates that we are "VOTING FOR OUR LIVES" in this election.

If you are unable to attend the event in Washington, D.C., contact Andrew Imparato, AAPD, at 800-840-8844 to learn how you can organize an event in your hometown.

The 2000 Executive Board ELECTION

YOUR ROLE IN SELECTING TASH's LEADERS

One of the most important things members of any organization are asked to do is to participate in selecting members of the Executive Board. Five of the fifteen seats on the TASH Executive Board will be vacated at the end of this year. This year the nominating committee has selected a slate of eleven extremely committed TASH leaders. TASH members are asked to vote for five of the candidates whose photos and statements appear in the following pages.

As described on the preceding page, this year, for the first time, we are offering four different ways to cast your vote -- by mail, fax, e-mail or via TASH's web site. To assure that every member votes only once, a Ballot Control Number has been printed on each ballot form. These numbers were applied by the printing company and we have no way of matching this number with your name or member ID. Remember that if you choose to vote by e-mail or via the web site, you will need to include your Ballot Control Number from the ballot form on page 9 of this *Newsletter* and that any replies containing votes for more than five candidates will not be able to be included in the final count.

Your vote is important! Please choose the voting method that works best for you.

THE FOLLOWING ARE THE NOMINEES FOR THE TASH EXECUTIVE BOARD OF DIRECTORS:

Paul Bates
is a Professor of Educational Psychology and Special Education at Southern Illinois University. For over 20 years, Paul has been a member of TASH and has served the organization for much of that time as a member of the JASH Editorial Board. Throughout Paul's career, he has been involved in innovative program demonstrations and advocacy activities that have highlighted the capabilities of persons with significant disabilities. These experiences have taught Paul the absolute need for professionals to listen with humility and respect to the wisdom of persons with disabilities and their families.

Recently Paul's professional interests have focused on person centered transition planning and self-determination. In these areas, Paul has been conducting interactive workshops involving students, their parents, and both school and post-school professionals. By learning together, the vision of an "enviable life" of community inclusion is shared, collaborative relationships are solidified, and true commitment is realized. Paul feels that he would bring a strong collaborative spirit to the TASH Executive Board, a spirit that should assist in building bridges to people and organizations that may currently have different priorities.

Paul is honored to have been nominated as a candidate for the TASH Executive Board and feels privileged about the possibility of serving the organization in this capacity. TASH has been a powerful voice for disability advocacy and has established strong consumer-professional coalitions. As an Executive Board member, Paul would advocate for policies and practices that would strengthen connections to the organization's past while building new coalitions and commitments toward realizing the goal of full community inclusion.

Rainee Courtnage
"I have been an advocate for inclusion since 1972, when my son Alex was born. I have spent the last 28 years actively advocating for public policy which recognizes each individual's rightful place in his/her community. My deep commitment to social justice issues has carried me through some challenging times as a parent and as a professional.

The realization of inclusion for Alex was a long and difficult struggle for us as a family, but the circle of friends we had around us made the journey worth the effort. We had to fight for every change that might insure that he'd have a good life. We became "experts" in positive behavior supports, in augmentative communication, in design and development of plans that would meet his wants and desires as well as his needs. We have remained active in many arenas — from legislative work, to meeting with other families, to just living a real life.
For the past six years, I have been an advocate for children and families in Denver. Previously, I worked as a resource coordinator for a private family support program, but am most proud of my years as a volunteer with local Arcs and Colorado TASH since 1987.

I served as an ARC board member in Montana at the time when public education was just becoming a reality, as a local and state Arc board member in Colorado from 1981 to 1994 (five of those years as state president), and on the Colorado TASH board in 1994-97 and again in 2000. During those years, I took advantage of every opportunity to become a more informed and better parent. Attending national TASH conferences has been a great way to keep myself centered and renewed.

Currently, I am involved with others in the revitalization of Colorado TASH. Our focus

Continued on page 5

2000 TASH Board Election

Continued from page 4

is to bring in new members, offer events that inspire and energize the membership and tackle public policy issues. I also serve as chair for Families and Allies working Together. This group organized to look at life for people beyond a "systems approach" - connecting or reconnecting individuals with their community.

My focus for many years has been in promoting positive behavior supports for individuals in schools, and this past year as a member of a statewide cross-agency training team. Providing as many avenues for communication as possible for individuals has also been a major interest and activity for me. The past several years the systems have been giving lip service to "self-determination" and "individual choice" while in reality, the exact opposite is happening. It is past time that we look at funding going directly to the person. Our systems are imploding around us yet, consideration for "another way" continues to elude the policy makers. I plan on being at the front on this one.

It is indeed an honor to be nominated for the National TASH board. I would bring a family and community living perspective to my work on the board. As a family, we have refused to give up and refused to listen to the naysayers. All Alex's life we have heard "He'll never..." Well, I'm here to tell you, "He did and he is..."!

Inclusion, self-determination, positively supporting someone all mean one thing: A Good Life. What's ordinary for you and me should never be extraordinary for my child or anyone else's. I will work hard to promote the vision and activities of TASH."

June Downing

is a lifetime member of TASH and a professor at California State University, Northridge. She is committed to creating the best learning environment for students with significant disabilities and their peers. To do so, she maintains high standards for teachers while helping them learn how to truly make all students, regardless of ability level, active members of fully inclusive classrooms. June does considerable inservice training, and has presented nationwide on inclusive and best educational practices to educators, family members, paraeducators, related service providers, and administrators. She shares her own experiences as a paraprofessional, teacher, work experience coordinator, and tutor to help others avoid mistakes she made, and to serve as a catalyst for creating change.

June strongly believes in the values of TASH and has been active at both the state and national levels. She was the Arizona TASH president for several years and is currently on the executive board of CalTASH as Vice-President. She has served and continues to serve on several TASH committees, including Personnel Preparation, Education, and Integrated Leisure and Recreation, and has reviewed proposals for the TASH international conference for several years. Publications include two books and numerous articles and chapters regarding inclusive education, teaching students to learn in inclusive classrooms, and personnel preparation issues needed to support inclusive classrooms.

June is interested in disseminating TASH values to other organizations to which she belongs, to faculty at different universities, teachers, and family members. She serves as a family advocate and is continually amazed when families who have a member with significant disabilities is unaware of TASH as an organization. Through her work with families, school personnel, and others, she hopes to increase awareness of TASH and what is possible when the vision for everyone is positive and builds on strengths and dreams. June would like to volunteer her energy and her commitment to serve to furthering the ideals that TASH represents.

Kathy Gee

is a lifetime member of TASH, and has been an active member since 1977. For over 20 years she has worked in school and community settings to promote the inclusion of individuals with disabilities in all aspects of life. Her bold leadership in the area of inclusive schooling has been focused on the use of respectful and effective support strategies which allow all children, especially those with the most significant disabilities, to feel honored, challenged, and successful in school as well as in community and family life. Kathy's work, as a teacher, teacher educator, researcher, advocate, monitor, and professor has always been done amidst the realities of the complex daily lives of children, youth, and adults, their families and friends, their teachers and support providers. She is well known for the amount of time she spends in classrooms, homes, and schools, working to develop successful ways for individuals to communicate, gain new skills and supports to improve their quality of life, and develop meaningful relationships and friendships to support their quality of life.

Kathy is committed to furthering progressive policies and legislation for individuals with disabilities. She has been an advocate for numerous children and youth and their families, assisting them as they assist their school system to realize both the spirit and the letter of the law in the IDEA. Through her projects and collaborative partnerships with schools at the California Research Institute and at the University of Kansas, she has assisted many schools and districts in their development toward effective supports and services, and inclusive schooling. Kathy is active at the California state level in developing LRE policy, an alternate assessment plan, and key performance indicators for the monitoring system.

Since her days as a teacher began in the late 70's, Kathy has been involved in numerous demonstration and research projects which have pioneered methods to support individuals with dual sensory and multiple disabilities within inclusive school settings and the community. Kathy and her colleagues developed methods for collaborating with general education teachers, and strategies for effective instruction within the general education curriculum. She has been the director of the Kansas positive behavioral supports project, and a member of the California team of trainers for the National Research and Training Center on Positive Behavioral Supports.

In private life Kathy has also been active in her own children's local school site councils, and in other community organizations. She has been a strong advocate for policies and practices related to diversity and inclusiveness related to ethnicity, gender, and sexual orientation. She has directly experienced the results of discrimination and the outcomes of support as a staunch advocate for her two nephews, now in their early twenties, who experience complex health and learning challenges.

Kathy is currently an associate professor at St. Mary's College in California. She is actively involved in TASH — presenting at confer-

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2000 TASH Board Election

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ences every year, running TASH Tech sessions, evaluating TASH conference proposals, serving on the specialized health care and Alice Hayden committees, and serving as a member of the JASH editorial board. If elected, Kathy looks forward to working closely with other TASH members to further develop and strengthen the goals of the organization; to ensure the ongoing advocacy, research, and policy initiatives which promote respectful supports and proactive self-determination for individuals with significant disabilities; and to collaborate with other like-minded organizations for whole school reform, policies which promote the well-being of children and families, and widespread celebration of diversity.

Donna Gilles has been actively involved with teaching individuals with disabilities, supporting their families, and training teachers and service providers for over 25 years. She has been a TASH member since 1978, has been a Governing Board member for 2 1/2 years and is currently serving as the Vice President and President-Elect. As a past (and current interim) president of Florida TASH, Donna is committed to strengthening the connection between TASH and its chapters.

Donna is the Associate Director for the Center for Autism and Related Disabilities and the Director of the Florida Outreach Project for Children and Young Adults who are Deaf-Blind at the University of Florida in Gainesville. Both projects provide technical assistance and training for families, school personnel, and other service providers who live with or work for people who experience a variety of significant disabilities. She has conducted preservice and inservice training for teachers and other service providers for 20 years at the Johns Hopkins University, the University of Maryland, and the University of Florida.

Donna feels that it is critical that people with significant disabilities, who are traditionally dismissed as incapable of having a voice, are given control over decisions which affect the current and future quality of their lives. Because of this, she is committed to the development of respectful teaching and support practices for people with the most significant disabilities. She feels that the abolishment of segregated work and congregate living options depends greatly on how well children and young adults with disabilities are educated in schools. In turn, the success of schooling is largely dependent on quality relationships that are created with and out of respect for people with disabilities.

Chris Kliewer's participation in the Peace Movement beginning in the mid-1980s brought him to direct action mobilizations across the United States, and ultimately raised his interest in issues of social justice for people with disabilities. In 1988, he moved to Syracuse, N.Y., and began teaching at the Jowonio School. "Jowonio" is an English transliteration of the Onandagan phrase meaning, "To set free." The school was founded as a part of the free school movement, and was one of the first educational sites to promote the full inclusion of all children. It was then that he became involved in TASH.

In 1995, he completed a Ph.D. in Teaching and Leadership at Syracuse University under the guidance of Doug Biklen. He is now a faculty member at the University of Northern Iowa, Cedar Falls, where he advocates for the full educational and community inclusion of all people. His research on the development of literacy skills in people with significant disabilities is helping to change school expectations and teaching methods. Currently, Chris is fighting for the release of an Iowan institutionalized against her will because she happens to have a disability.

Marcie Roth has been actively involved in TASH since the early 1980s. A lifetime member, she was TASH's Director of Governmental Affairs and Public Policy from 1995 until last summer, when she joined the staff of the National Council on Independent Living as the Director of Advocacy and Public Policy. Marcie is an active, daily presence in Washington, advancing the voices of people outside the beltway as decisions about disability public policy are made.

Marcie has been actively involved as a leader in the disability rights movement since the 1970's, spending many years assisting individuals to win their freedom from nursing homes and institutions and working on changing the systems that kept them from their communities. She has also been active in the inclusive education movement since 1983, and has advocated passionately for the rights of students with disabilities to receive the supports and services they need to be successful in general education classes in their neighborhood school.

Marcie spent several years providing training and technical assistance to school teams in dozens of schools prior to joining the staff of TASH. She was a strong leader in TASH's efforts to protect the Individuals with Disabilities Education Act during the recent reauthorization process.

Marcie is an active member of ADAPT, and is a founding member of Capital Area ADAPT, the Washington, D.C. area chapter. She also serves on the Board of Directors of the National Spinal Cord Association, the World Association of People with Disabilities and the Spinal Cord Injury Network of the Metropolitan Washington Area. She is the vice-chair of the Maryland Statewide Independent Living Council. Marcie's work takes her from the streets to cyberspace.

In addition to her personal experience with acquiring a disability, Marcie is also the parent of two children with disabilities. "My experiences in fighting for Jessica and Dustin's rights to an education and adequate, affordable health care have been the most significant lessons of my career. Despite all of my connections, all of my knowledge, my fight for educational services and health care that meet my children's needs has been awful. If this mom can't move systems to meet her children's needs, the system is going to be even less responsive to families with less experience and connections. This MUST change if we are to realize the dream of full community inclusion and meaningful participation for our children."

"It is with passion and a commitment to real change that I seek election to the TASH Board of Directors. I will bring a unique combination of skills and experiences to this role and will welcome the opportunity to continue to work toward a bright future for TASH and the people we are committed to."

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2000 TASH Board Election

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Susie Schaefer

"It is such an incredible personal honor to be nominated for the TASH board. As a long time member of TASH, the organization has and continues to be very important to me. The values of TASH and its mission are congruent with my own. My attendance at TASH conferences is historic. I have been a part of the TASH Multicultural committee for many years and served as the chair of that committee from 1995-97. I was on the TASH committee, originally known as the International Committee, that later became the Multicultural Committee. Work with this committee has included planning for Multicultural strands at the annual TASH conference, as well as annual committee meetings. In 1998, I served as co-chair of the local planning group for the TASH conference in Seattle. Much of my effort on this group focused on the formation of a local Multicultural committee. My goal was to involve individuals and families of color/ limited English speaking in TASH and in the conference. Of course, the best part of my involvement in the Multicultural and International work of TASH has been getting to know TASH members from an array of ethnic and cultural backgrounds from around the United States and other parts of the world.

Professionally, I am a long time (old) administrator with the state agency in Washington. One of the professional accomplishments of which I am most proud is my work with Washington families to redesign the state Family Support Program. Our primary emphasis has been to recognize and build upon the strengths of families and communities. During my 25 year career, I have also been involved in promoting systemic change that supports people to move from developmental centers to supported employment and institutions to community living. Most recently, my energy has gone towards convincing our state agency that governmental power is illusionary, and that individuals and families really should and really do have power and control over their own lives. I am now looking forward to leaving state government and finding different ways to provide greater opportunities for inclusion of a very diverse group of people and their families in their local neighborhoods, communities and associations.

I think I bring a background of varied experience (and some scars to show for it) and a very strong and active commitment to TASH and our multicultural work together."

Patti Scott

"I'm very excited to be nominated for the board! TASH is an organization that shares my deep commitment to making some major changes in the USA and beyond, so that ALL people get to have the same choices, opportunities and status that most of us seem simply able to take for granted.

What can I tell you about myself? Well, I joined TASH in the mid '80s and later served as Vice President of the New Jersey Chapter. I'm also a long-time member of the Community Living Committee, which I have been co-chairing with Judith Snow for the past two years.

I have been working as a direct service provider for almost 18 years now. In 1995, together with Kenn Jupp, I founded Neighbours, Inc., and took on the role of CEO for this non-profit agency that exists solely to enable people to design and live the life of their choice, irrespective of the degree of their disability. Now, five years later, over 100 people each have their own individual funding, rent or buy their own home, hire and fire their own staff, and follow their hopes and dreams to live their life in the way that they want. This year, we have begun to grow a network of tiny agencies that share the same vision and values, so that we can offer people the same personalized support system no matter where they live.

Right now, we have already extended from New Jersey into two counties in Pennsylvania and have opened a sister company in the United Kingdom, where we are working hard to make this a reality on the other side of the Atlantic. Additionally, we have provided consultation and support to people in a variety of countries (such as India and Malta) who share our commitment to an inclusive society.

It's great for me to have this chance to make a real contribution on the board of TASH and to help maintain the PATH that leads to a world of inclusion, harmony in diversity and true self determination that enables everyone to live full lives within their own neighborhoods."

Dick Sobsey

"I'm happy to be considered for the TASH Board. As Director of the JP Das Developmental Disabilities Centre at the University of Alberta in Canada, I teach courses in Inclusive Education and Communication Programming for Learners with Severe Disabilities, but most of my professional life is committed to research and advocacy. When I'm not working, most of my life is devoted to being father to a daughter in high school and a son who has a significant developmental disability and who attends regular class in our neighborhood elementary school. Although I've worked with people with significant disabilities since 1968, my last ten years as a parent have taught me some things that I don't think I would have ever learned through professional training or experience.

I believe that research must have social relevance. My research on violence and disability over the last decade has helped to call attention to how violence and abuse hurt so many people with disabilities. While there is much more work to be done, my work has had direct influence on the development of prevention and treatment programs as well as on law reform.

I believe that the greatest challenges facing people with disabilities are human rights issues. The lack of equal protection of the law in the form of medical discrimination and failure to aggressively prosecute crimes against people with disabilities are among the greatest dangers. That is why I've worked with government agencies on law and program reform in the U.S. and Canada, but also worked for people with disabilities in civil actions against those governments and against service agencies that have failed to meet their responsibilities. I can help TASH continue its strong tradition of human rights advocacy.

I believe that parenting is the most important role most of us will ever play in our lives. Services that require parents to act as paraprofessionals without considering how this affects their primary roles as parents can harm families. TASH can play an important

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2000 TASH Board Election

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role in gaining recognition for the unique roles of parents and other family members.

I believe that the lives of people with disabilities and their families are typically better than the bleak professional stereotypes often presented. As a researcher, I have found that most families of children with significant disabilities are healthy and strong. As a parent, I know having a child with a disability has been an asset to our family. TASH has done a great job of celebrating families, and I would like it to do even more to dispel the myth that all families of children with disabilities are "pathetic poster families."

I believe that TASH should maintain its primary focus on people with significant disabilities. Recent discussions about a possible broader focus for TASH foreshadow some of its coming challenges. If I am elected to the TASH Board, I will support maintaining TASH's primary commitment to people with significant disabilities. TASH can and should join with other groups who share common goals for social change, but only when doing so clearly serves this primary focus. Losing that focus could result in short-term gains by increasing membership, but the long-term result would be the sacrifice of many wonderful things that make TASH different from lots of other organizations."

Lu Zeph

"It is an honor to accept the nomination for the TASH Executive Board. My name is Lu Zeph, and I have been an active TASH member for over 20 years. During that time I have served on a wide range of TASH committees and work groups, and presently serve as a member of the Editorial Board of JASH.

My professional career spans over 25 years in the area of significant disabilities. I have been a teacher, an administrator and, for the past 20 years, I have been a professor at the University of Maine teaching in the area of significant disabilities and disability studies. In 1992, I became director of the Center for Community Inclusion, Maine's University Affiliated Program at the University of Maine. The Center's mission is to bring together the resources of the community and the university through education, research, and community activities that result in improved quality of life for individuals with disabilities and their families. The Center, like TASH, brings together individuals with disabilities, family members, and a broad range of professionals and other committed to what can best be described as "TASH Values."

I also have a strong interest in the area of public policy. Last year I was named a Kennedy Public Policy Fellow and had the privilege of serving for a year in Washington, D.C. as a congressional fellow with Senator Jim Jeffords, Chairman of the Health, Education, Labor, and Pensions Committee. This experience made me realize how important it is for organizations such as TASH to be at the table when legislation and policy decisions are being made that affect the lives of individuals with significant disabilities. I will bring this perspective, knowledge, and commitment that to the TASH Executive Board if elected.

In many ways TASH and I have grown up together. Like so many others, TASH has always provided me a place to replenish when the struggle to create change becomes overwhelming. TASH has always been there for me; the people, the values, and the commitment to do the right thing, even when it was difficult. I feel it is most appropriate for me to give back to an organization that has given me so much. In this way, I hope to contribute to ensuring that TASH will continue to do the same for others in the future."

……

And don't forget . . .

for the first time, we are offering four different ways you can cast your ballot!

Cast your ballot by mail, fax, e-mail or vote on TASH's web site. See details on page 3 of this *Newsletter*.

TASH IS SEEKING A

Coordinator of Governmental Affairs

The person in this position will:

- coordinate TASH's legislative and public policy advocacy efforts;
- represent TASH members and TASH's interests in Washington, DC
- maintain and strengthen TASH's presence on Capitol Hill;
- monitor national issues that impact on the lives of people with disabilities and their families and identify issues of importance to TASH and its members;
- draft statements on TASH's positions;
- build alliances with federal agencies and other disability and human rights groups;
- assure that TASH members have the information and tools needed to affect public policy;
- mobilize members to affect policy on a grassroots level; and
- disseminate information about TASH, its activities, agendas and positions.

FOR A COPY OF THE JOB DESCRIPTION, INCLUDING POSITION REQUIREMENTS, PLEASE SEE TASH's web site at www.tash.org or call 1-800-482-8274. To apply, send a letter of interest, curriculum vita/resume, and salary requirements to: GA Search Committee, c/o Nancy Weiss, Executive Director, TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. **Applications will be accepted until October 1, 2000.** TASH is an Equal Opportunity Employer and encourages individuals with disabilities and family members to apply for this position.

TASH 2000 Election of Five (5)
EXECUTIVE BOARD MEMBERS
Term of Office: 2000-2003

- OFFICIAL BALLOT -

There are five positions for members of the TASH Executive Board to be filled this year. Positions will be filled via ballot by dues-paying TASH members (one each) in accordance with the Association's By-Laws. The Executive Board members-elect will begin their terms at the Annual Board Meeting held in conjunction with the 2000 TASH Conference to be held in December in Miami Beach, Florida.

Ballot Instructions:
You should vote for a total of FIVE nominees. Ballots containing more than five votes are invalid. Please mark your ballot in ink.

☐ **Paul Bates**
☐ **Rainee Courtnage**
☐ **June Downing**
☐ **Kathy Gee**
☐ **Donna Gilles**
☐ **Chris Kliewer**
☐ **Marcie Roth**
☐ **Susie Schaefer**
☐ **Patti Scott**
☐ **Dick Sobsey**
☐ **Lu Zeph**

For information about the candidates, please refer to pages 4-8 of this issue of the TASH *Newsletter.*

Mailing Instructions:
Ballots may be returned using this postage-free mailer, or originals of the ballot can be sent in an envelope. If you elect to use an envelope, please be sure the word BALLOT is printed on the front. If you use an envelope, please do not place anything other than your ballot inside.

You may also return this ballot by fax (410-828-6706) or on TASH's web site: <www.tash.org> (see button marked: Board Election 2000). You will need to enter your Ballot Control Number (printed in the box below) in order to vote from the web site. Finally, each TASH member for whom we have a valid e-mail address will receive an e-mail inviting you to vote by return e-mail. Even if you do not receive an e-mail from us (meaning we do not have your correct e-mail address!), you can vote by e-mail. Send an e-mail by October 10, 2000 to: <ballot@tash.org>, listing the five candidates for which you would like to vote. Remember, if you vote via the web site or by e-mail, you must include the Ballot Control Number.

Ballots must be received at the TASH Central Office by October 10, 2000

Mail your completed ballot to:
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Baltimore, Maryland 21204
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Ballot Control Number

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Doing Justice: Criminal Offenders with Developmental Disabilities

BY JOAN PETERSILIA, Ph.D.

People with cognitive, intellectual, or developmental disabilities are a small but increasing portion of offenders in the criminal justice system. Generally this population is referred to as having mental retardation or being developmentally disabled (MR/DD), though the second term is now preferred.

People with developmental disabilities are estimated to comprise 2% to 3% of the general population, but represent 4% to 10% of the prison population, and an even higher percentage of those in juvenile facilities and in jails. Officials believe the problem is likely to worsen over the next several years, as the prevalence of MR/DD in the general U.S. population increases.

A just-completed study by the author conservatively estimates that 15,518 Californians with developmental disabilities are currently in jail, in prison, on probation, or on parole. The study's findings also indicate that California has few programs or policies to accommodate the special needs of people with developmental disabilities, who often lack access to the legal protections that exist for others (Petersilia 2000).

Studies show that many — if not most — people with MR/DD who become involved with justice authorities have mild disabilities that are not easily recognized by people who are not specifically trained to recognize them. As a result, most people with developmental disabilities proceed from arrest through adjudication without any special accommodations to help them negotiate the complex justice system. Although state law requires people with hearing impairments to have language signers and non-English-speakers to have interpreters in their dealings with the justice system, similar assistance to people with developmental disabilities is not required.

Since people with developmental disabilities who are arrested may not understand their rights (such as Miranda warnings), they frequently waive them and end up in jail pretrial. When questioned by the police, they often give answers they believe the police want to hear, rather than answers that are correct. During court proceedings, they are less able to assist the defense in case preparation, and frequently make self-incriminating statements. While some research suggests their crimes are likely to be less serious, on average, than those of people without disabilities, their rates of conviction and incarceration are higher than those of people without disabilities. Although we do not wish to excuse the criminal behavior of offenders who have cognitive disabilities, we must recognize that people with this label cannot be processed like others who come into contact with the criminal justice system.

Once in jail or prison, people with developmental disabilities are often victimized by other inmates. Because of their cognitive disabilities, they are more likely to have a difficult time understanding jail and prison rules and may spend time in segregated conditions — which limits their work opportunities, and hence "good-time" credits and early release.

Because there are few specialized rehabilitation or parole programs for reintegrating people with developmental disabilities once they are released, their entrance into the revolving-door cycle of prison to parole and back to prison is predictable. At an average annual cost of $22,000 per year per U.S. inmate, such a scenario should offend our cost consciousness as well as our sense of equal justice.

Legal scholars and advocates for people with disabilities are becoming increasingly vocal in their concern about mistreatment from justice agencies. While trend data does not exist, there is a sense that the prevalence of the problem

"...Of all societal institutions, the criminal justice system is the last to adequately respond to the needs of people with developmental disabilities. For people with developmental disabilities, the criminal justice system is the last frontier of integration."

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Doing Justice: Criminal Offenders with Developmental Disabilities

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is growing, and that the justice system has been particularly slow to accommodate the needs of people with disabilities. As Ruth Luckasson, a member of the President's Committee on Mental Retardation, recently wrote:

"We can quibble about whether education or medicine has responded more quickly to the societal need to end discrimination of the mentally retarded...but I don't think there is much question that of all societal institutions, the criminal justice system is the last to adequately respond to the special circumstances of people with developmental disabilities. For people with developmental disabilities, the criminal justice system is the last frontier of integration" (Luckasson 1999:2, italics added).

What Explains the High Prevalence of Criminal Defendants and Inmates with Developmental Disabilities?

A number of cumulative factors appear to explain the high prevalence of people with developmental disabilities in the justice system:

➪ Offenders with MR/DD come disproportionately from low-income minority groups, where police presence and the probability of arrest are high. Fully a third (34%) of adults with disabilities live in households with total income of $15,000 or less, compared to only 12% of those without disabilities.

➪ Official justice system processing (from arrest through sentencing) usually proceeds without officials becoming aware of the offender's intellectual disability. McAfee and Gural (1988) found that 75% of offenders with mental retardation were not identified at arrest, and more than 10% were not identified until they were in prison.

➪ Justice personnel are unfamiliar with how to recognize the disability, and offenders with mild retardation can be clever at masking their disability. A survey of 100 police officers found that 91% of the respondents had no training in working with individuals with developmental disabilities. A similar lack of training was also found for judges and lawyers (Schilit 1989).

➪ Once arrested, MR/DD offenders are usually jailed during pretrial proceedings, as they are unlikely to meet the criteria for personal recognizance or bail, since they are most likely unemployed and have limited or non-existent support systems, two of the major criteria used in bail decision-making. Research has shown that persons held pretrial, all other factors being equal, are more likely to be convicted (Toberg 1992).

➪ Studies show that MR/DD defendants are more easily convicted and receive longer terms than offenders without disabilities (Laski 1992). They confess more readily, provide more incriminating evidence to authorities, and are less successful in plea-bargaining (Edwards and Reynolds 1997; Gudjonsson 1990). Leo and Ofshe (1998) reviewed 60 cases of well-documented false confessions and identified about one-quarter of those as suspects with mental disabilities.

➪ Once incarcerated, the MR/DD offender is often abused or victimized. Their response to threatening situations is more likely to be physical rather than verbal or intellectual, and their resulting institutional behavior is poor. As such, inmates with MR/DD take up an inordinate amount of staff time, and many are eventually reclassified to a higher and more expensive security level.

➪ Their poor institutional behavior and "over-classification" means that they fail to earn maximum good time/ work time credits, are unable to participate in early release programs, and in states with parole, fail to become "parole eligible" because they have not finished the programs required for parole consideration. The result is that offenders with MR/DD serve a greater portion of their court-imposed sentence than non-MR/DD offenders (Lampert 1987).

➪ In most prison systems, only inmates who score above the 6th grade school level are enrolled in vocational training programs. If inmates with MR/ DD cannot meet this criteria, they are denied all but the most menial jobs, and are rarely able to obtain any sort of paid employment in the prison system. As a consequence, incarceration for inmates with MR/DD has a more devastating impact than for offenders without disabilities (Cowardin 1997).

➪ When released, MR/DD parolees are rarely placed in specialized supervision caseloads or given added assistance, and they often are explicitly excluded from rehabilitation programs because of their disabilities. Their resulting recidivism rates are high (Petersilia 1997).

Another significant problem is the number of people with mental retardation who are executed, although 12 states and the U.S. Federal government now have laws prohibiting the execution of people with mental retardation. At least 30 people with mental retardation have been executed since 1971, and experts estimate that as many as 10% to 15% of the 3,000 men and women on the nation's death row have a developmental disability (Miller and Radelet 1993).

Justice-related education for people with developmental disabilities and their families and/or care providers must be increased. People with MR/DD must have access to education that enhances their ability to protect themselves from criminal victimization and avoid possible criminal activities.

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Doing Justice: Criminal Offenders with Developmental Disabilities

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What Must Be Done?

Real change in the way people with developmental disabilities are treated in the criminal justice system will require state and national leadership. The highest priority must be given to requiring that people with developmental disabilities who are arrested are given assistance prior to being questioned by police. Such advocates must understand both mental retardation and the criminal justice system. This change will also require continued training for police officers. Many states currently provide training on disability issues to new police recruits, but most of it relates to mental illness and not mental retardation.

Leadership support on this issue has been slow nationally. As one lawyer put it, "This is not a shouting population." Because of their perceived powerlessness, coupled with stereotyping and prejudice, people with developmental disabilities have never attracted the kinds of funding or policy attention that their numbers in the justice system should warrant. Excellent program models and proposed legislation exist, yet most of it sits on shelves.

Three other priorities must be addressed. There must be an increase in justice-related education for people with developmental disabilities and their families and/or care providers. People with MR/DD must have access to education that enhances their ability to protect themselves from criminal victimization and avoid possible criminal activities. If they do become involved with the criminal justice system, they and their families need to better understand their legal rights (including those that can be requested under the ADA).

Justice system personnel also need training, as most are unfamiliar with the needs of persons with disabilities. Several professional organizations have developed materials to assist in this education. For example, the National Judicial College has developed a training curriculum for judges, entitled "Defendants, Victim's and Witnesses with Mental Retardation: An Instruction Guide for Judges and Judicial Educators." Similarly, the Arc of the US has updated a training package originally developed by the International Association of Chiefs of Police about how to interact with people with mental retardation.

We must also develop appropriate sentencing options, including community-based rehabilitation programs, for offenders with developmental disabilities. When released, the majority of parolees with developmental disabilities are virtually never placed in specialized caseloads or given added assistance, and they are often explicitly excluded from treatment and work programs because of their disabilities. There appears to be agreement that the current system is not working and that something better must be developed. Judges reported being unable to divert these offenders to the community because few appropriate programs exist. Correctional administrators should give specialized probation and parole caseloads highest priority, to reduce the recidivism rates of offenders with developmental disabilities.

Policymakers and social services agency staff often express a desire to address these problems, but note the practical realities of a lack of resources. The national tough-on-crime mood inhibits them from improving services for a select few, however deserving. Nonetheless, available research evidence indicates that well-designed and properly implemented programs can result in significant reductions in recidivism. Massachusetts, New York, Texas, and Ohio all operate successful programs for parolees with MR/DD.

Most states do not have such programs, and most offenders with developmental disabilities are released to communities that provide few services and impose conditions that almost guarantee their failure. The result is an increased number of parolees returning to prison, putting pressure on states to build more prisons—which, in turn, limits money available for rehabilitation programs that might have helped offenders when they were in the community.

This situation presents a formidable challenge to those concerned with prisoners with disabilities. Ultimately, of course, reform will come only when there is willingness to accord a basic dignity to all citizens regardless of intellectual level, and take seriously everyone's constitutional right to "equal justice for all."

Joan Petersilia is Professor of Criminology, Law & Society at the University of California, Irvine. Professor Petersilia may be reached by e-mail at jrpeters@uci.edu

HAVE YOU CONSIDERED BECOMING A LIFETIME MEMBER OF TASH? NOW IS THE TIME!

The price of a TASH Lifetime Membership has not increased since the inception of this membership option almost 20 years ago. Lifetime memberships are currently priced at $1,000. This cost can be spread over multiple payments if you choose. Once you are a lifetime member, you never need to pay TASH membership dues again. Lifetime members are recognized in the TASH *Newsletter* and in each year's conference program.

The TASH Executive Board has approved a price increase for Lifetime Memberships from the current rate of $1,000 to $1,300, effective January 1, 2001. We hope you will take advantage of the opportunity to become a Lifetime Member of TASH at the current $1,000 rate. To find out more or to arrange to pay for your membership over several payments, call Rose Holsey at 1-800-482-8274, ext. 100 or send an e-mail to rholsey@tash.org.

Serious Issues Facing Today's Victim and Offender with Mental Retardation

BY LEIGH ANN DAVIS, M.S.S.W., M.P.A.

"I don't know how to recognize mental retardation. But if there are certain guidelines, certain hints about how to recognize people with this disability, then maybe we should know about them...maybe if we were a bit more aware of things to look out for."[1]

This straight-forward and insightful quote from a police officer emphasizes the point that most people in the criminal justice system — whether victim advocates, attorneys, police officers, judges, correctional officers, forensic specialists or other professionals in the criminal justice system — do not know what mental retardation is or how to recognize it. They often do not have knowledge or familiarity with the disability, and lack the confidence to effectively work and communicate with individuals with disabilities. Even though efforts to train criminal justice professionals have been ongoing in some states and have just begun in others, the "invisibility" of mental retardation still remains one of the most critical issues facing people with mental retardation in the year 2000 and beyond. Without accurate identification of mental retardation among victims and defendants, they can not obtain the support needed to fully participate as equal citizens in the criminal justice and legal system.

Victim Issues

The seriousness or level of attention given to a social problem is often determined by the number of people impacted by the problem. In the case of victimization against people with disabilities, this problem qualifies as extremely serious because individuals with disabilities are more likely to become a victim of crime compared to those without disabilities. The National Organization for Victim Assistance addressed this issue in a 1998 bulletin that discussed how victim advocates and others in the criminal justice system can work with crime victims who have disabilities. The bulletin stated that people with developmental disabilities (which may include mental retardation) have a 4 to 10 times greater risk of becoming a crime victim than those without a disability (OVC Bulletin, 1998).

People with mental retardation are more vulnerable to all types of victimization, including neglect, financial abuse, physical abuse, sexual abuse and rape. With regard to sexual victimization, many people with any type of disability (including physical and mental) will be sexually assaulted or abused (Sobsey & Varnhagen, 1989). Some research suggests that people with an intellectual disability are at the highest risk of abuse compared to those with other types of disabilities (Sobsey & Doe, 1991). Rape is also a common experience in these individuals' lives. Approximately 15,000 to 19,000 people with developmental disabilities are raped each year in the United States (Sobsey, 1994).

Victims with mental retardation are often alone, without the aid of any practical coping tools or assistance, after a victimization occurs. Individuals with mental retardation may not realize they are being victimized and, therefore, will not tell anyone about the crime or it may be too unsafe to report the crime. The Arc and NOVA (National Organization for Victim Assistance) are working together on a project funded through the Office for Victims of Crime (OVC) to create materials for victim advocates and disability advocates in an effort to improve services to victims with mental retardation and other related developmental disabilities. Throughout the past year of this project, issues raised by disability and victim advocates include:

◆ How can victim assistance and disability organizations work closely together in an effort to reach out to victims with mental retardation?

◆ What services or treatment options, if any, are available for victims with mental retardation in my community? (i.e., counseling services, rape crisis services, support groups, behavior support services and self-protection training)

◆ How can the various state or county agencies responsible for helping victims work together (or should they)? (organizations include the local victim assistance program, the district attorney's office, the protection and advocacy center, and the adult or child protection agency)

◆ What types of abuse or victimization are considered criminal in nature when the victim has mental retardation? (states' laws vary with regard to what is considered a crime)

Sorting through these issues takes time and determination by disability and victim advocates. There are some initial positive signs because advocates from both fields seem genuinely concerned about this population. However, a commitment by disability and victim advocates at all levels of the system must be made to reach out to victims with disabilities in an effective manner.

Offender Issues[2]

Many may not perceive the issue of people with mental retardation becoming

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[1] Taken from Cleartalk: *Police responding to intellectual disability* by Mark Brennan & Roslin Brennan, 1994).

[2] The term offender is used to describe someone who either has committed a crime or who has been accused of committing a crime.

Serious Issues Facing Today's Victim and Offender with Mental Retardation

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involved in the criminal justice as serious — until one's own son, daughter, or other family member is faced with this possibly life-threatening situation.[1] Although there is no link between mental retardation and criminal behavior (i.e., people with mental retardation are not more likely to commit crimes), there is a greater chance that someone with mental retardation would be caught if he or she were involved in criminal activity. It is not uncommon for people with mental retardation to be used by non-disabled criminals to commit crimes because they are easier to persuade, manipulate and scare into doing things compared to those without mental retardation. People with mental retardation have a deep, strong need to feel accepted and may agree to help with criminal activities to gain friendship. Once in the criminal justice system, they are more likely than others to be convicted, sentenced to prison and victimized (Santamour, 1986).

Regardless of one's professional title or which field of endeavor one pursues, each of us must work toward improving our understanding and awareness of issues facing today's victim and offender with mental retardation.

There are specific concerns regarding different types of crimes committed by individuals with mental retardation. For example, in some states, programs that serve offenders with mental retardation have a higher number of sex offenders in their program compared to those with other types of offenses. Does this mean that people with mental retardation are more likely to commit sexual offenses than those without disabilities? Not necessarily. One researcher found that approximately 10-15% of all sexual offenses are committed by people with mental retardation. This is only slightly higher that those committed by the general population (around 9%) (Murphy, Coleman & Haynes, 1983). Most of these "offenses" occur out of ignorance, lack of education or poorly developed self-control. One example is that of a man charged with indecent exposure when urinating in the street. His real crime was not knowing how to find the public restroom and being unaware that such behavior is socially unacceptable (Cooper, 1995).

Sex offenses among people with mental retardation are often over-represented in many studies. For example, researchers found that people with mental retardation were more likely to be involved in sexual misconduct (12.5% of those with mental retardation compared to 1% without a disability) (Koller, Richardson & Haynes, 1982). Although research is inconclusive on whether people with mental retardation commit more sexual offenses or whether they are more likely to be caught when they do, experts in the field generally believe the latter. What is known, however, is that people with mental retardation are at increased risk for sexual abuse and victimization (and other types of abuse) which may have a direct impact on their involvement in the criminal justice system as a sex offender. They may learn illegal sexual behaviors and continue doing them with no knowledge that the behavior is a crime.

Today's offender with mental retardation is often without appropriate services or programs to 1) help the person stay out of the criminal justice system in the first place; and 2) assist the person once he or she becomes involved in the criminal justice system. People with disabilities need ongoing education to help them learn what and who is safe, how to talk to police officers and how to protect their rights as citizens. Professionals in the criminal justice system must receive training on how to identify someone with a disability and know the most appropriate placement/treatment available to the individual. Research is needed to validate and specifically pinpoint what types of services or programs for offenders with mental retardation would be most effective. For example, what counseling techniques work best for physically abused individuals with mental retardation or what components are needed to have a successful program for sex offenders with mental retardation? With accurate and reliable data, disability and criminal justice advocates can request funding for programs to address unmet needs among this population.

Conducting research builds and broadens our knowledge base on victim and offender issues. On the national level, creating a national or international center to study, research and consistently monitor issues involving people with mental retardation in the criminal justice system is one possible step for long-term progress in achieving a more balanced system of justice. On the community level, building coalitions of professionals from all sectors of the criminal justice and disability fields that focus solely on disability and criminal justice issues can help build awareness of the problem.

Regardless of one's professional title or which field of work in which one is involved, each must work toward improving his or her understanding and awareness of issues facing today's victim and offender with mental retardation. As the quote from the police officer stated at the beginning of this article, "maybe if we were a bit more aware of things to look out for," we could identify people with mental retardation, reduce injustice in

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[1] Author and advocate Robert Perske writes books about people with mental retardation who are accused of serious crimes and unknowingly waive their Miranda rights, end up on death row and are sometimes executed - even though there is no evidence that the defendant is guilty.

Serious Issues Facing Today's Victim and Offender with Mental Retardation

Continued from page 15

their lives and increase the quality of life for both victims and offenders with disabilities.

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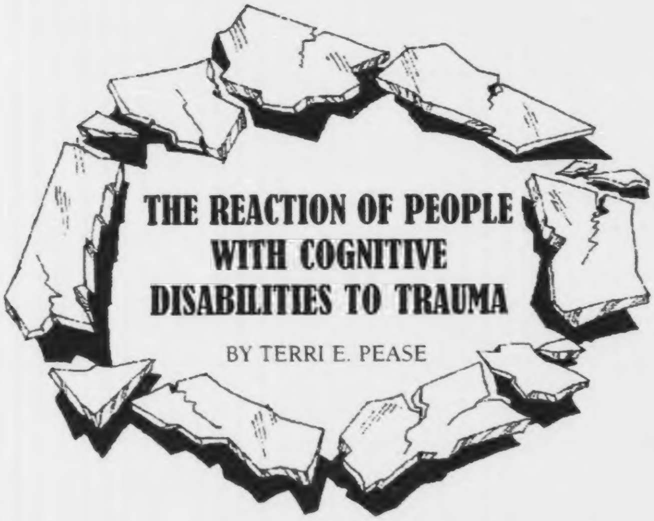

THE REACTION OF PEOPLE WITH COGNITIVE DISABILITIES TO TRAUMA

BY TERRI E. PEASE

Psychiatrist Judith Herman has said that traumatic events "overwhelm the ordinary systems of care that give people a sense of control, connection and meaning." Such events occur, and occur often, in the lives and histories of people with developmental disabilities. However, despite increasing attention to the mental health needs of adults with developmental disabilities, we continue to behave as though having a developmental disability somehow confers immunity to trauma. For too long, we have held to a myth that a person with significant cognitive disabilities will not remember, or be affected by experiences like sexual abuse, physical injury, restraint, pain or overwhelming helplessness. Of course that is not the case.

Our continuing faith in the efficacy of behavioral interventions for people with cognitive disabilities makes the lack of response to overwhelming events in the lives of people with disabilities especially tragic. So much of what is done with, to and for people with developmental disabilities in the name of treatment is predicated precisely on the idea that they will experience what happens around them, retain what they experience, and in response, change their behavior. When people with cognitive disabilities retain the experiences that are planned by caregivers, and change their behavior in the intended way, we call it learning, and applaud them and ourselves. Of course, these very same people will also experience, remember and be affected by overwhelming experiences that disconnect them from the sense that the world is safe, predictable, that people are ordinarily well-meaning, and that their actions and wishes have an impact on the people and things around them.

People are changed by trauma. When the changes brought on by trauma disrupt their lives, intruding into their memories, and restricting their ability to enjoy life and to connect with others, they are experiencing post traumatic stress disorder, PTSD.

Statistics to clarify the risk of PTSD to people with developmental disabilities are not directly available. However, studies of the criminal justice system suggest that people with developmental disabilities will experience four times the general rate of violent crime. Others have estimated that more than half, and as many as 80% of women with developmental disabilities experience sexual assaults—a kind of trauma that sharply increases the risk of PTSD.

Of course, not all traumatic events come from abuse. Automobile accidents, surgery, natural disasters and war are all frequently cited sources of the kind of overwhelming helplessness that is called trauma. Other events that are commonplace in the lives and histories of people with developmental disabilities, restraint, assault by out-of-control peers, and painful medical procedures among them, also cause overwhelming fear and helplessness. Thus, it is certain that people with developmental disabilities are subjected to overwhelming events at a rate that makes trauma a major, unrecognized risk to their well being.

Working Through Trauma

Although as many as half of people in the general population in the United States, and as many or more among people with developmental disabilities, will experience an overwhelming event that brings on terror and helplessness, not all of these traumatized people will go on to suffer the intrusive memories, avoidance of reminders and constricted life that are the hallmarks of post traumatic stress disorder. Human beings attempt to make sense of trauma, to work through the experience by telling and retelling the story, changing both their view of the event, and the meaning it has for them, in the process. When this process is successful, the person, although he or she may be changed forever by the event, is able to move on to a life that is largely free of disruptive memories, emotions and reactions to what happened to him or her.

The kind of working through of trauma that avoids PTSD involves both emotional and cognitive processing. It requires that the person contain and regulate the strong emotions unleashed by the experience while using language and past experience to make some meaning out of the event. At the same

> "Remembering and telling the truth about terrible events are prerequisites both for the restoration of the social order and for the healing of individual victims." Despite limitations of verbal and cognitive functioning, with proper supports people with developmental disabilities can often heal from trauma.

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time the traumatic experience can cause lasting neurobiological changes that affect the way that trauma survivors process and integrate memory, and respond to fear. We know that children's less developed ability to contain and regulate their emotional responses causes them to react to, and retain trauma differently than do adults. However, while it is well understood that having a developmental disability can affect the brain's ability to manage emotional response and regulation, cognitive processing and encoding of memory, we simply do not know how having a cognitive disability interacts with the impact of trauma to affect a person's ability to handle and recover from one or more such events. We do know that a significant proportion of traumatized people—somewhere between 8% and 20% in the general adult population—go on to experience lasting and disruptive changes in their functioning as a result of trauma. A similar rate, at least, would be the case for people with developmental disabilities.

Recognizing and Responding to Post Traumatic Stress Disorder in people with Developmental Disabilities

Probably the overwhelming majority of cases of post traumatic stress disorder among people with developmental disabilities are not recognized. Many of the symptoms of PTSD—long standing avoidance of, or extreme reactions to ordinary experiences or objects, unexpected outbursts of rage or terror, intermittent or lasting withdrawal or dissociation, repetitive accounting of past events, sleep abnormalities and self-soothing with drugs alcohol or self-injury,—tend to be understood as idiosyncratic features of a person's disability. However, these are all easily recognized by those who work with trauma survivors as signs of a possible post-traumatic response. It may be that PTSD goes undiagnosed in people with cognitive disabilities because of the sheer impact on systems of care that would come with understanding just how many people are troubled, afraid and impaired by their past experiences. And, in many cases, professionals with the expertise to care for developmentally disabled adults with PTSD are in short supply. Instead, medication is used to control outbursts, masking the symptoms while doing little to relieve the underlying impact of the lasting memory of a terrifying experience.

In the growing professional literature on PTSD little attention is paid to the specific treatment issues that arise when a tramatized person also has a cognitive disability. One exception to the lack of focus on disability in the PTSD literature is the six-part protocol for addressing PTSD among the developmental disabilities population, developed by psychiatrist Ruth Ryan.

She recommends judicious use of medications for treating concurrent psychiatric conditions, while also requiring medical intervention, avoiding iatrogenic complications (for example paradoxical reactions to medications or programming which re-evokes a traumatic event), psychotherapy, habilitative changes and education and support for staff. With all of these elements in place, people with developmental disabilities and PTSD can experience significant relief.

In addition, there is growing self-help literature on PTSD, which includes information for those who love and support people with PTSD. Many of the suggestions in these sources can also be applied to those who support adults with developmental disabilities. Beyond that, David Pitonyak has described ways to offer supports for people with cognitive disabilities who also have PTSD. Among these recommendations, he emphasizes helping to tell the person's story "in a way that you would want your story to be told," helping the person to achieve a sense of safety and well-being, to expand and deepen his/her relationships, to have more fun and to have more control over his or her symptoms.

What both of these strategies have in common is taking seriously the attempts by people with developmental disabilities to tell, in words when they have them, in behavior and in their bodies, that they have been profoundly afraid and that they need help to restore their sense of safety and connection to the world. Judith Herman reminds us that "remembering and telling the truth about terrible events are prerequisites both for the restoration of the social order and for the healing of individual victims." Despite limitations of verbal and cognitive functioning, with proper supports people with developmental disabilities can often heal from trauma.

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Teaching Personal Safety

Studies show that people with developmental disabilities are at higher risk of criminal victimization and face innumerable barriers when reporting their victimization, having their case investigated and prosecuted, and in receiving emotional support. Barriers include lack of awareness about the extent of victimization experienced by people with disabilities, communication difficulties for the person reporting the victimization and/or the person receiving the report, and understanding the trauma caused by victimization.

Research tells us that the trauma experienced by crime victims with disabilities is just as severe as the trauma experienced by people without disabilities. Additional barriers include lack of sexuality education, social skills, vocabulary and co-operative multi-agency services.

In principle most family members and professionals acknowledge all people have the right to make decisions about their lives, to be secure from violations of their bodies and personal space, and to live in a society free from violence. " All people" includes people with disabilities, no matter how significant their disability. The "dignity of risk" is a fundamental building block in human development. Society (parents, educators, law enforcement, disability and victim service professionals, self-advocates, etc.) has the responsibility to educate and empower individuals regarding these rights.

Teaching personal safety/ sexual assault risk reduction strategies is a life long activity. Each human developmental step affords us the opportunity to provide appropriate sexuality and personal safety information. Without the necessary vocabulary, understanding of appropriate social/ professional relationships, and knowledge of their right to say "NO," and receive support, people with developmental disabilities will not only continued to be victimized, but will be re-victimized by the systems developed to protect them. Parents and professionals have to be encouraged to examine their own beliefs, biases, concerns and fears regarding people with disabilities self-determination, including sexuality and relationships. These issues then need to be discussed in relation to developing intervention strategies and facilitating healing in an attempt to reduce victimization. Personal safety/sexual assault risk reduction education is a continuum. General safety guidelines should be at one end and sexual assault risk reduction guidelines should be at the other end of the continuum.

Terri E. Pease, Ph.D., is Program Director-Victim Services at Safe Horizons in New York City. Dr. Pease's specific interest is in working with adults with cognitive disabilities on issues of sexuality, sexual assault and relationships. She is associated with the Institute on Disabilities-UAP at Temple University and will be part of the Criminal Victimization and People with Disabilities panel at the TASH 2000 conference in Miami Beach in December.

Dr. Pease may be reached by e-mail at TerriEPease@aol.com

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

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Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

THE NEVER-ENDING STORY: ENDING IN HAPPINESS

BY AUDREY BADGER

It's been several years since I've read the collection of newspaper articles that tell the story of the "unfortunate incident" that disrupted the life of our family and appears in my mind even now -- seven years later -- as a horrible nightmare. This one act of violence lies deep in the minds and hearts of a father, a mother, a brother, and the victim herself -- my daughter, who has Down Syndrome.

I reviewed the newspaper clippings in order to present an accurate account of the events that took place from May 1993 until January 1999. How naive of me to think that I would have forgotten even the slightest detail of what had occurred. As I read, I knew that I had not.

The newspaper headlines read as follows (and are listed here in the order in which various parts of the saga took place):

- (1995) "Alleged rape victim found competent to stand trial"
- (1996) "University of Penn. student found guilty"
- (1996) "University of Penn. student sentenced for rape"
- (1998) "Penn. student convicted of rape appeals to Supreme Court"
- (1998) "Supreme Court rules man needs new rape trial"
- (1999) "Man escapes charges of raping mentally challenged young woman"
- (1999) "Resident freed; charges dropped"

The story began with the rape of a young woman with Down Syndrome who was lured into a secluded area only a few yards away from her home. The suspect was a neighbor living four houses away from us.

After the rape, the suspect was convicted by a jury and was given a 5-10 year sentence.

A year and a half later, the suspect's family filed an appeal and the verdict in the case was eventually overturned. The suspect was set free and is now preparing to become an attorney. However, our story doesn't end there.

There are no headlines that tell the story of the present. How today, 7 years after the attack, our daughter, now 27, continues to endure the scars left behind as a result of the crime committed against her.

She no longer goes out into our neighborhood alone. Not since that day in 1993. Nor does it seem she will return to the many hours of enjoyment that she once experienced riding her bike and greeting neighbors as she rode throughout our development.

Everyone knew her and loved her! Now everyone misses her "hellos" and warm smile because she remains inside listening to music or watching videos. Fear has griped our daughter's life.

Everyday she goes through her usual ritual of checking each door and window in our home to see if they are securely locked. Our daughter is presently seeing both a psychologist and a psychiatrist who is able to dispense the medication that she takes. She has been diagnosed as having post traumatic stress disorder (PTSD).

Our daughter has flashbacks, hallucinations, and shows signs of depression. The medications help some, although the side effects and weight gain are troublesome.

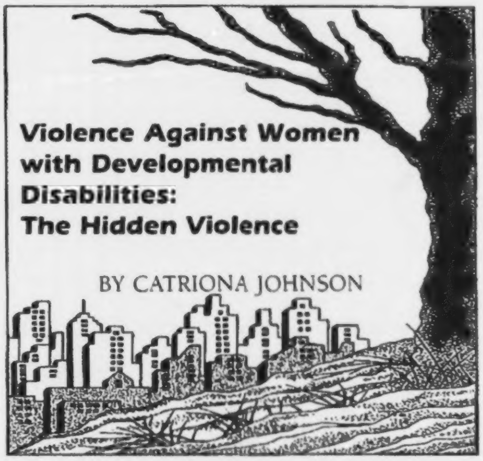
We try to keep her involved in various activities such as Special Olympics and her job as a school cafeteria worker. While these endeavors do help to keep her involved and occupied, we continue to pray that the memories that are vividly with us all will one day be replaced with happier memories in our lives. We firmly believe that with God's help these things are possible and that our daughter will once again become the happy, secure individual that she once was.

Audrey Badger will participate in the panel discussion, Criminal Victimization and People with Developmental Disabilities, that will be held at the 2000 TASH annual conference in Miami Beach, Florida, December 7-9.

There is still time to submit a proposal to present a poster session at the 2000 TASH Annual Conference. If you would like to receive an application, or if you need additional information, please contact Kelly Nelson by e-mail <knelson@tash.org> or by phone at 410-828-8274 ext. 105.

Violence Against Women with Developmental Disabilities: The Hidden Violence

BY CATRIONA JOHNSON



Every year in America an estimated 3 to 4 million women are beaten by their life partners. Every year, 1,000 women are killed by their husbands, boyfriends, and former partners. Studies show that 18% of women report being sexually assaulted or raped in their lifetime (Department of Justice, 1998). Nearly three decades of research, work by battered women's shelters and crisis centers, and a variety of interventions have revealed that these statistics are not limited by income bracket, race, region of the country, or population density. Yet within the area of violence against women, women and girls with disabilities remain underserved. Despite evidence showing that gender based violence is perpetrated against women with disabilities at a rate much higher than the general population of women, there is a paucity of information, expertise, and services available to them. When the conversation turns to gender-based violence, women and girls with developmental disabilities are usually left out.

According to research, most people with disabilities will experience some form of sexual assault or abuse during their lifetime (Sobsey and Varnhagen, 1989). Victims who have some level of intellectual disabilities are at the highest risk of sexual violence (Sobsey and Doe, 1991). Persons with developmental disabilities have a 4 to 10 times higher risk of becoming crime victims than persons without developmental disabilities. One study of alleged crimes against people with disabilities revealed that 90% involved sexual offenses (Carmody, 1991). Both males and females with developmental disabilities are victims of sexual violence, however women experience sexual violence at a higher rate than their male counterparts. Sobsey cites 78.9% females compared to 21.1% of males in research from the University of Alberta (Sobsey, 1994). Consistent with this, a number of other studies on rates of sexual assault against women with developmental disabilities reveal that over 80% had been sexually assaulted (Hard, 1986). Of those who reported being sexually assaulted, almost 50% had been assaulted 10 or more times (Sobsey and Doe, 1991).

Lenore Walker, who introduced the idea of the cycle of violence, described battered women: "Battered women include wives or women in any form of intimate relationships with men" (1979, xv).

In the case of women with developmental disabilities, the description becomes more blurred. An "intimate relationship" could also be defined as one with a caregiver, attendant, or personal assistant-individuals who interact with these women at the most intimate levels (personal care or health care for example). Studies reveal that the largest group of offenders are disability service providers; 67% who sexually assaulted or abused people with severe to profound cognitive disabilities contacted their victims through specialized disability services (Sobsey, 1994). Turk and Brown report that 98% of sexual assault/abuse offenders are male (Turk and Brown, 1992) and Margolin reported that, controlling for relative caregiving time, male caregivers abuse those in their care more than 6.5 times as often as their female counterparts (Margolin, 1992). This fact, coupled with the overwhelmingly sexual nature of the abuse and assault, leaves no doubt that the majority of crimes that women with developmental disabilities experience are gender-based. The parallels between domestic violence and caregiver violence are clear. Domestic violence is a pattern of coercive behaviors that may include physical, sexual, and/or psychological assaults, in addition to social isolation, deprivation, and intimidation. When a woman with a disability is put in physical danger, or controlled by the threat or use of physical force by an intimate partner or caregiver, she is a victim of domestic violence. This crime is motivated by a need for power and control. The perpetrator uses fear and the threat of physical harm to control his victim. Very often the perpetrator controls the individual's access to financial resources. He may use his physical and economic control to limit the victim's access to transportation and medical care, particularly if her care requires regular appointments.

Inherent within the framework of the caregiver/client relationship is the potential for abuse, particularly when the victim is isolated or segregated from traditional community relationships and supports. According to the literature on domestic violence, a key predictor of being a victim of domestic violence is social isolation and lack of social support (Straus et. al., 1980). This is of particular concern for women and girls with developmental disabilities, who report less social activities and less involvement in community life than their non-disabled peers. According to the International

> There is a general assumption that crime victims with developmental disabilities do not need or require legal action, nor are they competent to testify once in the legal system. ..."incidents" against these victims are judged to be "abuse and neglect" rather than crimes subject to the criminal court system. Consequently, offenses are handled through administrative channels within a group home or institution.

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Violence Against Women with Developmental Disabilities

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Center for the Disabled, 56% of persons with disabilities report that their disability prevents them from getting around, attending cultural and sports events, or socializing with friends outside their homes as much as they would like. This figure rises to 67% among somewhat severely disabled individuals and to 79% among very severely disabled individuals. (Louis Harris and Associates, 1986).

Complicating all of this is the general assumption that crime victims with developmental disabilities do not need or require legal action, nor are they competent to testify once in the legal system. According to Alan Abeson, Ed.D., former executive director of The Arc of the United States, these "incidents" are judged to be "abuse and neglect" rather than crimes subject to the criminal court system. Consequently, offenses are handled through administrative channels within a group home or institution. A woman with a developmental disability who is raped may not have a choice about bringing charges, and is therefore unable to use the judicial system. If she does gain access to the criminal justice system, she will likely interact with police, attorneys, judges, and victim services that have little experience in prosecuting a case in which the victim has a developmental disability.

In 1997, the Administration on Developmental Disabilities (ADD), in response to the alarming statistics and an overall focus on domestic violence by the Department of Health and Human Services, funded four projects of national significance addressing violence against women with developmental disabilities. The Metropolitan Organization to Counter Sexual Assault in Missouri, Travis County Domestic Violence and Sexual Assault Survival Center in Texas, the Oregon Health Sciences University Center on Self-Determination, and The Arc of Maryland were each selected to develop innovative programs, publications, and research to reduce violence against women with developmental disabilities. Descriptions of each of the projects are available on the ADD's website at http://www.acf.dhhs.gov/programs/add/pns02.htm.

The Arc of Maryland's Personal SPACE Curriculum

While a number of promising, widely scattered curricular responses to violence against women with developmental disabilities have been developed, in researching such curricula The Arc of Maryland did not find one that had embraced the self-advocacy movement in all aspects of the curriculum -- development, training, and evaluation. In Maryland, self-advocacy projects and the Self-Determination Initiative support the belief that people with developmental disabilities should live in their communities, where they also need to be safe.

In 1997, The Arc of Southern Maryland formed a partnership with the Calvert County Abused Persons Program to train their staff on working with women with developmental disabilities, and those involved in the training wanted to build on that success. The Arc of Maryland had experienced phenomenal success with its Know Your Rights project, a training workshop developed and taught by people with developmental disabilities that educated others about their rights, and the Ask Me! Project, a quality assurance project in which people with developmental disabilities interview others receiving services through the State Developmental Disabilities Administration about their satisfaction with the services they receive.

Building upon the success of those projects, The Arc of Maryland's Gender Violence Prevention Research and Development Team, a group consisting of women with disabilities, family members, and experts in sexuality education, person-centered planning, counseling, sexual violence, and program evaluation, began the process of developing a violence prevention curriculum that would be taught by women with and without disabilities.

The mission of the Personal SPACE (Safety, Planning, Awareness, Choice, Empowerment) program is to empower women with disabilities to take greater control of their lives by increasing their ability to protect themselves. It is hoped that the program will increase participant self-confidence, improve problem-solving and decision-making skills, including ability to problem-solve with peers and intimates; and produce heightened assertiveness and improved communication skills. The eight core classes in the curriculum are:

1. Orientation
2. Sexuality
3. Healthy Relationships
4. Sexual Harassment
5. Sexual Assault
6. Domestic Violence
7. When Someone Who Cares for You Hurts You
8. Safety Planning

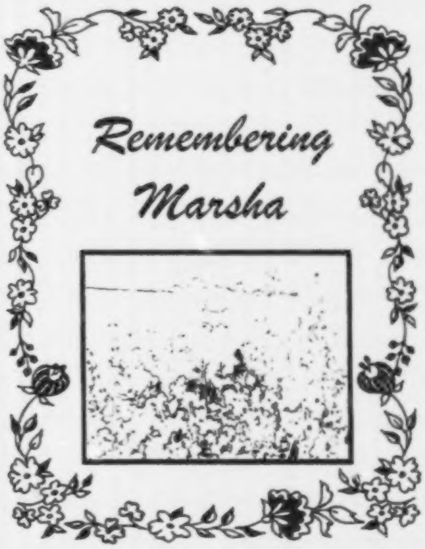
A ninth class, self-defense, is recommended, but is typically done by self-defense experts.

The success of The Arc of Maryland's project will be based on whether the curriculum can produce measurable changes in knowledge and attitudes about violence among those women exposed directly to the curriculum and thereby reduce violent incidents in women's lives, potentially influencing their resiliency to domestic and sexual violence.

The Personal SPACE curriculum will be finalized and available through The Arc of Maryland for interested parties by October, 2000.

Catriona Johnson currently works for the Maryland DD Council. She may be contacted by e-mail at <catrionaj@md-council.org>

Additional information about the Personal SPACE curriculum may be obtained by calling the Arc of Maryland at 410-974-6139.



Remembering a Friend, Marsha Forest

Doug Biklen

Well over 20 years ago I was in Toronto to give a speech on inclusion. After the speech, Marsha Forest wanted to talk about creating a Summer Institute on Inclusion, to be based at the Roeher Institute in Toronto, and sponsored by McGill University in Montreal. For my wife and I that began a series of summers where we would travel to Toronto and Montreal to teach two week-long, intensive courses on inclusion and qualitative research, respectively.

It was an exciting time, for in many ways this was in the very early days of classroom inclusion for students with significant disabilities, and Marsha knew that with her Summer Institute, she had a chance to influence an entire nation, as teachers from British Columbia to Nova Scotia would come to learn about inclusion and then return to their communities to effect change. Little did we know that her work would in years hence become international.

Many of us at TASH will always think of Marsha whenever we see flyers placed on seats at plenary sessions, for it was Marsha who introduced this strategy of grassroots communication. It seems that for years, at each of our annual conferences, no matter what time of day the plenaries were held, every seat would have a flyer for Marsha's Summer Institute, as well as a copy of Inclusion News. I never saw who put them out on the seats, so all I could do was imagine Marsha and a cadre of collaborators scurrying around, laughing and socializing as they got the job done.

Marsha, Gunnar Dybwad and Jack at the 1997 TASH Conference in Boston.

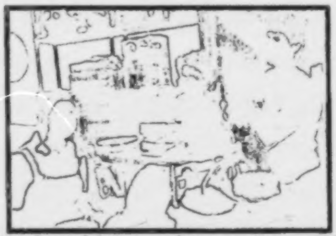
Marsha had a wonderful sense of humor, always critical, always subversive, always humanizing. She loved to laugh. She loved to conspire for change. She loved to bring people together.

The other day I was thinking about all of the people who Marsha introduced me to who then had a significant impact on me. I won't try and list them all, but I can't help mentioning a few. Rose and Dom Galati and their daughters Felicia and Maria, Linda and King Till and their daughter Becky, Catherine Woronko and her father Stan, and of course Judith Snow. Rose Galati is a teacher and staunch inclusionist who, along with the Woronkos and Tills helped me see that the one place in society where full inclusion really does exist, no holds barred, is in some families. I spent many evenings talking to the Galatis, watching Toronto Blue Jays baseball games with them, visiting the girls' schools, and learning from them about how they were making inclusion work, even when at first the schools were reluctant, even obstructionist toward them. Rose has a way of building community, of creating space where her daughters could make friends, where others could appreciate who they were. When Marsha first introduced me to Rose, the introduction was filled with the most glowing, reverential praise for this "wonderful woman." That was Marsha, she took such pride in finding people who were open minded, people who liked to stand up for change, people who wanted to be part of a social movement.

Marsha and Rose Galati at the 1999 Toronto Summer Institute.

Linda Till was working at a nursing home/institution when she met Becky, then a small girl with cerebral palsy who for all intents and purposes had been left at the institution. Linda became attached to Becky and then arranged, with her husband's help of course, to adopt Becky. In the years that followed they became advocates and litigants for school inclusion. As she got older, Becky became an advocate in her own right. They are leaders. This, of course, was one of Marsha's gifts, to see people who have leadership qualities and to help build support around them, to ally with them, to create change.

I only know the story second hand from friends and from a Canadian radio news report about Judith Snow and the Joshua Committee that Marsha helped form to support her. Judith was living in a nursing home, cut off in many ways from the world when Marsha met her and began to talk to her about getting out and getting engaged in social change. Who could have predicted that Judith would come to be one of the leading disability rights thinkers and activists in the world? Marsha could.


Marsha, Judith Snow and Norman Kunc in 1979.

It was through Marsha that I met: Gordon Porter, a leading advocate for inclusion in New Brunswick; and Margie Brown, an inclusion professor and advocate and parent in Nova Scotia; Joe Whittaker, and inclusion professor and activist in the middle of England; and Norman Kunc! Yes, Norman too. At the time he had just written a little book called Ready, Willing and Disabled. Marsha seemed to know so many people. She was the ultimate networker of people working at the grassroots level. I'd say that we have no idea how much Marsha's networking power will be missed until it finally sinks in in the months ahead that she is no longer with us, except that I know she taught a lot of us well. The people she connected with are all networkers themselves.

Marsha's Summer Institute classes became gathering places for conceptualizing change

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Remembering Marsha Snyderman Forest
August 15, 1942 - June 2, 2000

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(L-R) John McKnight, John O'Brien, Judith Snow, Jack and Marsha

but also for meeting those directly involved in it. It was in Toronto that I first had the experience of teaching a class about school inclusion where people with significant disabilities were in the class, along with nondisabled friends. One of the people whom Marsha invited, Catherine Woronko, had difficulty with speech, but her high school peers had learned a lot about what she liked to do from her other ways of communicating. Together this young woman and her friends hung out in the class, and from time to time the friends contributed their ideas about school life to the discussion we were having on inclusion. If anyone ever lived her ideas, Marsha did.

There are many other things I will carry with me about Marsha. Some mainly personal. Each summer that my wife and I traveled to Canada to teach, Marsha somehow arranged a house for us to be house sitting in while someone she knew was away for the few weeks we were in town. And one summer she scheduled for our young children to attend an inclusive summer program that she had created. All over Toronto there were summer Get Together Programs that Marsha was instrumental in founding; our son and daughter attended the Winona Street Get Together, just a few blocks from Marsha and Jack's house and from the house she had arranged for us to stay in. And I remember that each day Marsha would grill our kids about what had gone on at the program, what they had learned, who they had met, where they had gone on field trips. She was so genuinely interested in them, and they loved her for it. She engaged them in conversation, and they knew she took them seriously. We were so lucky to have had this time together and for our kids to know Marsha.

During those summers I especially remember how Marsha introduced us to the best, and probably smallest, Thai restaurant in Toronto, the Thai Shan Inn. Of course Marsha was long since friends with the family that owned and ran the place. In fact, she seemed to know the people and their children at every restaurant in town. Thai Shan really was tiny, and it had the best, and often hottest Thai food around. I've never found a better green papaya salad anywhere. Marsha loved to tell us about great, inexpensive, ethnic restaurants, and often went with us to them, including Malaysian, Carribean, and Chinese, as well as fantastic Vietnamese noodle shops . She also liked introducing us to Just Desserts, a remarkable dessert place that had rows of pies and cakes to choose from, at least 50 every day. And more often than not, as we'd make our way through these, we did so with small crowds -- Marsha, her husband and collaborator, Jack Pearpoint, and lots of friends. Wherever Marsha went, making friends was intimately connected to making change.

Marsha, Herb Lovett and an unidentified friend.

During the past 15 years or so, TASH became a special place for Marsha. It was at TASH that Marsha found, as many of us do, one place that truly welcomes parents, people with disabilities, researchers, teachers, community inclusionists, and other professionals collaborating together, and where there is an unshakeable commitment to inclusion and other forms of social justice. Marsha didn't just come to participate, she came to create. She introduced a "strand" of sessions that became one big community, creating projects, creating plans, and making commitments to effect change. Marsha brought diversity to TASH, bringing in new members, lining up keynote speakers, pushing inclusion in new directions. One year TASH met in Chicago and Marsha brought a large group of teenagers from an inclusive school program to talk about inclusion from their perspective. For many of them, this was their first experience to speak in front of an audience, and Marsha made it happen.

I don't know how to stop talking about Marsha. And of course I won't. Marsha, you taught us so well. Most of all, we know you loved us. TASH is so rich for having had you as a teacher, member, collaborator, and friend.

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I met Marsha when I was a graduate student at the University of Wisconsin in 1981. If I think about it now, I can only remember a couple of things about this first encounter. I remember thinking that Marsha was not of this earth with her ideas about full inclusion. I may have even rolled my eyes. Most of all I remember her energy. It was all over the room and it was this that moved me to consider her ideas about full inclusion.

Over the years we became friends. I was in Texas with her at the time she discovered her first breast lump. I was so sure that she would be fine. After that we talked and e-mailed; and always bargained over the price of books she wanted to sell through the Inclusion Press. Her openness and directness was always a challenge to me. One time Jay Klein brought me a Polaroid of her and Jack taken to assure me that they were fine. It is still on my bulletin board with another of her talking passionately, with her hand on her heart, to a group of teachers in their first encounter with that energy.

I know her contribution and her effect. She helped me see a different world.

By Jan Nisbet

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Marsha and Shafik Asante in 1997

I remember Marsha

Anne M. Donnellan

When I remember Marsha, I see her surrounded by balloons and drawings and many, many people making lots of noise. People who live diversity. Not just us walking, talking white folk who so often exclusively inhabit the space as we talk about

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Remembering Marsha Snyderman Forest
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Marsha, age 2

diversity and inclusion. She was always surrounded by people who lived the issues and Marsha cared for and about them at least as much as the issues.

Marsha was a wonderful spirit for change. She took on complex issues and systems and brought them to the human level. Inclusion was possible and critical because it made possible the human connection. She lived her own life to the fullest, treasuring each day as she raced ahead to outlive her own human frailty and illness. And she did it on rollerblades for heaven's sake!

I didn't always agree with Marsha. At times, that was because she was so far ahead of me. Even when I disagreed, I admired her spirit and her intention. She played a unique and important role in all our lives and at our meetings. I don't know who will do it in her stead.

At TASH in Miami I'll be looking for the crowd, listening for the noise and the laughter and hoping there will be at least a few balloons to remind us that the true measure of our effectiveness is how well we connect and enhance the human spirit in our own lives and those whom we mean to serve.

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Never doubt the power of friendship
Jeff Strully

In 1980, my wife and I were travelling to Toronto to attend a conference. Prior to leaving Kentucky for the conference, a mutual friend, John O'Brien, had told us about Marsha Forest and the work that she was beginning to do helping to think about children in schools alongside their non-disabled peers, in integrated recreational programs such as the Summer Get Together, and the development of circles of friends. While at the conference we found ourselves on the elevator with a very energetic, enthusiastic and loud woman from New York. We knew immediately this must be Marsha Forest. That started a 20-year professional and personal relationship and friendship that has not only changed our lives, but the lives of so many others around the world.

While no one person is responsible for the inclusion movement, Marsha deserves much of the credit on pushing this issue in a very public way. She wrote, lectured, and practiced inclusion in all parts of her life. She became a beacon pushing for all children to learn together. Her lectures were filled with raw energy and excitement about the possibilities of all children learning together. She believed with all of her heart and soul that all children can and should learn together. I was on the TASH Conference Committee at that time and had suggested to Lou (Brown) that Marsha would be a wonderful speaker at our conference. While Lou had some doubts, he supported this idea. Marsha's lectures at TASH were thought provoking and inspirational. She pushed the audience to think outside of the normal boundaries for students in school. She pushed TASH to move forward in its support of inclusion for all students.

High school graduate Marsha (1959)

She knew the power of children and the critical importance of friendship in people's lives. Marsha, Jack Pearpoint (Marsha's husband), and Judith Snow were the first people involved in thinking about circles of support/friendship. She not only lectured about friendship and circles of support, she also was personally involved. Marsha could light up a room with her stories and passion about the power of friendship. She excited many families and educators to think about and work on friendship for all children.

Marsha came up with many other ideas such as the integration facilitator role. While the story is a long one, Marsha hired Anne Marie Ruttiman, who was the first integration facilitator, to help Katherine find her place in school. This started the integration facilitator role, which has helped many children become included in their local school.

Marsha, along with Jack, Judith, and John (O'Brien), was interested in figuring out how to think about and plan for better futures for people by developing PATH and MAPS. They came up with interesting and different ways to think about a brighter future for people. Throughout the world today, on walls everywhere, people have bright, colorful and exciting plans being thought about and worked on because of their efforts.

Marsha enjoyed eating Chinese food, scuba diving, travelling, reading, and spending time with friends. But most of all, her husband, Jack, was always in the center of everything she did and thought. Marsha's love for Jack was always very apparent and beautiful.

If you can answer the question "have you made a difference during your lifetime or not?" then the only answer is that Marsha made a significant difference during her life. It wasn't so much the products (MAPS, PATHs, Circles, and Inclusion facilitator) that she produced, but the energy, excitement, values, beliefs, and heart that she brought to us that really mattered.

Over the past 20 years, my relationship with Marsha has been close and personal and at times, more distant. Our paths have gone in the same direction and in different directions over the years. There were times we did not see each other as frequently as I had or maybe she had wanted. Then there were times such as in San Francisco several years ago that we got away just the four of us (Jack and Marsha and Cindy (my wife) and I) for Chinese food, rich desserts, wonderful conversation and lots (and lots) of laughs. These were the times that were the best and that I will always remember forever and ever. Thank you for being my friend!

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Marsha Forest
Dave Hingsburger

A small group of parents gather to talk about their children's future. The discussion is changed from only short years ago. Now they talk about relationships, about work, about a life expected. Without knowing it these parents are paying tribute to a woman whose vision, for their children yet unborn, was one of full participation in life and in society. These parents have children who have always been included - always been home. It was a hard won battle, too soon forgotten. Fought by a Forest who never lost sight of the trees.

I remember the first time I saw Marsha Forest. She was presenting at a conference co-sponsored by the education system along

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Unequal Protection, Unequal Justice

BY DANIEL D. SORENSEN

Mary, which is not her real name, is a woman with psychiatric disabilities who had been doing quite well. A friend of mine who works in a sexual assault program told me her story. She was living on her own in midtown Sacramento. Her psychiatric symptoms were under control.

Then, one day, her condition flared up. A man on the street saw her on her balcony and realized that there was no one to help her. He forced his way into her apartment and raped her. He told some of his friends. First one, then later another also came to her apartment and raped her.

But her ordeal wasn't over. She was unable to seek help because of the severity of her psychosis and the trauma of the rapes. Finally, a neighbor noticed that she was in some difficulty and reported it and she got some help. Help but no justice, as no arrests were made in this case.

SIZE OF THE PROBLEM

Mary's case is not rare. Eighty percent of women with disabilities similar to Mary's have been sexually or physically assaulted according to one study. There is a real but largely unknown epidemic of violence against people with significant disabilities in our society. Stories like Mary's, as horrible as they are, tend to got lost in the crowd of crime stories that we experience every day in the media. As the father of a son with significant disabilities and as a long-time advocate for people with disabilities, I have known too many such crime victims over the years.

Research tells a disturbing story. Dick Sobsey, the leading expert in this field, reports that there is general agreement among experts that people with significant disabilities experience serious crime at a rate four to ten times higher than the general population. One of the best studies, done by Wilson and Brewer, found that the rate of sexual assault was 10.7 times higher for people with intellectual disabilities (mental retardation) than for the general population and 12.7 times higher for robbery. A study of a group with a different type of disability found similar results. It surveyed 278 residents of group homes for people with psychiatric disabilities in Los Angeles. The study found that this group had a rate of serious crime that was 9.5 times the rate of the general population.

Professor Joan Petersilia is a nationally renowned criminologist and the former director of the Division of Criminal Justice of the Rand Corporation. She testified in 1998 before a California State Senate panel that the total number of serious crimes against people with substantial disabilities exceeds the total number of crimes involving elder abuse, hate crimes or domestic violence. Unfortunately, most of the Senate panel members were away on business during Professor Petersilia's testimony, leaving the panel's chairman virtually alone to hear about this crisis in public safety.

The numbers are particularly grim in the area of rape and sexual assault. The four principal research studies on this topic have found that over 80% of women and 30% of men with intellectual disabilities have been sexually assaulted. The most thorough of these studies found that 80% of those women who have been sexually assaulted have been assaulted more than once and 50% have been assaulted more than 10 times.

How could such a dramatic problem of focused violence in our society go generally unnoticed? Wouldn't we hear about this and know about this if it were really happening? This problem has not been the first of its type to go unnoticed. Child abuse, elder abuse and domestic violence all share a similar history.

Decades ago people did not believe there was a widespread problem of child abuse, nor did they hear many reports of child abuse. They simply were unaware of its existence other than as a very rare occurrence. Gradually, over decades, it has emerged as a recognized major social problem. Elder abuse and domestic violence experienced a similar history. The issue of violence against people with disabilities is now beginning to make this same slow journey.

> There is a widespread belief that the testimony of victims or witnesses with certain disabilities will not stand up in court since their testimony is "unreliable." This belief among prosecutors, jurors and judges does, in fact, make these cases difficult to win. But this belief is more a part of the pattern of stereotypes and discrimination than a reflection of reality.

REPORTING OF THESE CRIMES

I knew five women with intellectual disabilities, each in their 30s, who lived in a California foothills community. They lived in a group home run by a man and his wife. The women were good

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people, kind and dependable. But something was wrong and I could never figure out what. I often asked them if there was anything wrong. They always told me everything was fine but with a sad, nervous glance away as they said this.

One of the women formed an especially close friendship with one of the staff where she worked. She finally, fearfully and bit by bit, eked out the story of what was happening to her. The owner of their group home was systematically raping her and the other four women. This had been going-on for the last five years. They had been terrorized and were too afraid to report these crimes. If that one woman had not developed such a close friendship with that staff person and found the courage to report on the person who had extraordinary power over her life, these crimes might still be continuing to this day.

The experience of these women illustrates a central problem. The high rate of crime against this population is bad enough. What makes it even worse is that so few of these crimes are reported or, if they are reported, few are believed. In this particular case it took five years before it finally got out. Police, prosecutors and the courts can not take action when they are not informed of crimes.

Every police department, sheriff's office and district attorney that I have consulted in California reported that they have very few cases involving crime victims with disabilities, dramatically less than the rate of serious crime against this population would predict. This is a practical indication that these crimes are being reported at a much lower rate than for other crime.

For decades, the Seattle Rape Relief Project has worked with victims of sexual assault with developmental disabilities. They have concluded that there is a greater underreporting of cases involving victims with developmental disabilities than of other populations. More dramatically, another study found that only 3% of cases of sexual assault involving people with developmental disabilities are ever reported to authorities. This compares with a reporting rate of sexual assaults of 32% for the general population.

Why is this? One reason is that there is a widespread perception among people with developmental and other more significant disabilities, their families and advocates that reporting crimes may often be useless. I can't count the number of times I have been told, "why should I report the crime, nothing is ever done about it."

There is evidence that by far the largest single number of perpetrators of these crimes are care providers. They are in a position to suppress the reporting of these crimes and to pressure their victims into remaining silent. This is also one of the reasons for the higher number of repeat crimes, as they often continue to victimize people under their care as they actively prevent their victims from reporting the crimes.

In Canada, a University of Alberta study found that residents of care facilities who had been criminally abused, as well as non-abusing staff, were reluctant to come forward for fear of reprisals or retribution from administrators.

I believe that administrators may find themselves in a situation that to report a violent crime can lead to negative publicity which may involve questions about their competence, damage their careers, or even lead to losing their jobs. Minimizing the severity of the reported criminal abuse, or deciding that it was unlikely that a crime occurred, avoids such risks.

INVESTIGATION AND PROSECUTION

I was giving a talk about violence against people with disabilities to an advocacy group, when one of the board members, Jane (not her real name) started to silently cry. She then got up and left the room.

As soon as I had finished, I followed her out to the hall to apologize. Jane, who was in her 40s, told me her story. She said that her father and brothers had raped her as a child. She was then sent to an institution as she had a mild intellectual disability.

She lived in this institution (not in California) for the next 30 years. She said she was sexually assaulted at least once in each of those 30 years. She reported each and every crime, but there were no arrests or prosecutions in any of those cases. She left that institution and has finally lived the last eight years of her life free of sexual assault.

One prosecutor from a southern California district attorney's office casually announced in a meeting that, "We never prosecute sexual assaults against victims with intellectual disabilities because you can't win them." Fortunately, an Alameda county prosecutor immediately responded by stating that, "We routinely prosecute such cases and we win most of them."

There is a widespread belief that the testimony of victims or witnesses with certain disabilities will not stand up in court since their testimony is unreliable. This belief among prosecutors, jurors and judges does, in fact, make these cases difficult to win. But this belief is more a part of the pattern of stereotypes and discrimination than a reflection of reality.

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> *The President signed the Crime Victims with Disabilities Awareness Act into law in 1998. This law requires that, for the first time, the National Crime Victims Survey collect information on crime victims with disabilities. This survey is the single most important source of information about the rate of violence and crime in America.*

Nitza Perlman did a study in Toronto on the accuracy of the testimony of adults with intellectual disabilities compared to university students. She found that the testimony of the adults with intellectual disabilities was equal in accuracy to the testimony of the university students. As in Alameda, these cases can be prosecuted and won with the right skills, attitudes and with reasonable accommodations to the specific disability of the victim or witnesses.

Dick Sobsey reviewed a number of studies on this topic and reported that they all reached at least one common conclusion: that convictions of these offenders are rare in spite of the chronic and severe nature of the crimes. He stated that overall there is not good prosecution of these cases but that it varies greatly across different criminal justice systems.

Sobsey also reports that a number of studies have found that potential perpetrators have a belief that they are unlikely to be arrested or prosecuted for crimes against this population. A psychologist at Atascadero State Hospital told me that he had overheard two sex offenders talking. One said to the other, "Get a job in the D.D. (developmental disabilities) system when you get out, it's easy pickings."

HOPE

The good news is that all this is beginning to change. There is a growing awareness of the problem of crime and violence against people with disabilities. California's Governor Gray Davis has proposed a first in the nation state government program to address crime and violence against people with disabilities. This initiative has the potential to become a national model. Gray Davis issued a statement during his campaign for governor stating that, "I will be a leader in ensuring that our citizens who have substantial disabilities receive the full protection of the law and equal justice." His "Crime Victims with Disabilities Initiative" contained in his recently released budget delivers on this campaign promise.

The President signed the Crime Victims with Disabilities Awareness Act into law in 1998. This law requires that, for the first time, the National Crime Victims Survey collect information on crime victims with disabilities. This survey is the single most important source of information about the rate of violence and crime in America. The act also requires the U.S. attorney general to conduct a national study on crime against people with disabilities.

From nationwide conferences to a U.S. Justice Department seminar to federal grants in five cities, national awareness is growing. The results of the Department of Justice study on crime against people with disabilities will be presented to the U.S. Congress and will stimulate recommendations for further action that the Congress and the administration should take to address this problem.

Many people are now watching and hoping for more substantive reforms. People with disabilities comprise over 10% of the population and if you add their family members, the total represents over 40% of the population or some 14 million Californians. We are slowly and inevitably waking up to the reality that we, and our loved ones, are not receiving equal protection or equal justice.

Maybe someday stories like Mary's or Jane's or the five women I knew from the foothills will be far less commonplace. But this will happen only if we all demand that our leaders and our institutions act to address violence against citizens with disabilities.

Daniel Sorenson is Chair of the California Victims of Crime Committee. The Committee was founded seven years ago as a statewide coalition composed of over 30 organizations of consumers, advocacy groups, state agencies, service providers, labor and criminal justice organizations. It has worked to educate its members, the government and the public about crime and violence against people with disabilities.

Questions about the Committee's work or the information contained in this article may be directed to Mr. Sorenson at dsorense@dmhhq.state.ca.us

Silent AUCTION EVENT

Have you ever thought about the distinctive characteristics that make your state or country such a unique place in which to live? We would love for you to share the tastes, sights and sounds of your favorite places with others who may not have a chance to journey to your corner of the world.

Why not make a donation to the TASH Silent Auction?! Not only is the fair market value of all donations tax deductible, but proceeds from the auction will benefit the TASH Conference Scholarship Fund. The Fund is used to assist people with disabilities, parents and other family members to attend future TASH conferences.

If you would like to make a donation or find out more details, please contact Priscilla Newton, Director of Marketing, at 410-828-8274, ext. 102 or send an e-mail to pnewton@tash.org

Law Enforcement Awareness of Autism: In Memory of Calvin Champion, Jr.

BY DENNIS DEBBAUDT

On Sunday, April 30, 2000, Calvin Champion Jr. went on the last day trip of his life. While in the care of a paid personal attendant, the 32-year-old non-verbal Nashville man, who had autism and mental retardation, died after an altercation with responding police officers outside a Babies "R" Us store in Nashville[1]. Calvin died surrounded by people who had little or no knowledge or training about autism, predictable situations of concern and care, or autism recognition or approach techniques—knowledge and training that may have saved his life.

Following are some of the tragic facts of the Calvin Champion Jr. case and suggestions on how we, as advocates, can better support critical care workers and law enforcement professionals when they work with or come into contact with persons with autism. There is a loud cry for public awareness coming from the autism community for recognition of critical issues of safety and risk in the community which comes at the same time as these issues are being addressed with new informational, awareness and educational tools.

Described by health professionals who worked with him as a "gentle man"[2], Calvin's last day started with an ominous decision: despite the post-incident assertion by Tom Nebel, a Champion family attorney, that Calvin's records at the agency responsible for his care indicated that he should have been kept away from "stressful, new situations" and that he didn't "do well in crowds"[3], his personal care worker took Calvin, along with her 3 year-old son, into the children's apparel store that day[4]. "She set the chain of events in motion where Calvin became agitated, Nebel said[5]. The care worker was a graphic designer with three weeks of experience working with people with disabilities when the incident occurred. The care worker insisted, "I got full training, all I needed."[6]

Nashville police said this is what happened:

Champion, a resident of a group home run by an agency that contracts with the state to provide services to people with disabilities, was taken to the store just before 2:30 p.m. by the caretaker and her son.

Upon leaving the store, Champion, who has difficulty communicating, started moving from side to side and rocked the van while seated in the back seat.

Then he patted the 3-year-old on the head, causing the child to cry. The caregiver couldn't get Champion under control and let him out in the store's fire lane.

After the woman got out of the van, Champion took her hand and patted himself on the head, which is supposed to be a calming influence, and grabbed the caregiver's shirt and tore it. Fearful, she locked herself and her son inside the van, calling police.

A responding officer arrived to find Champion hitting himself in the head with his fists and open hands and hitting the van. When the officer went to check on the woman and child, Champion came around the van toward her.

The officer backed away, but Champion lunged at her and grabbed her shirt, a police spokesman said. She pepper-sprayed him and he released his grip.

Champion went into the store, grabbed clothing and wiped his face. The officer then got him to come out into the foyer. After two other officers arrived, Champion came at Miller again, this time grabbing her by the throat. Another officer used pepper spray and all three officers fought to restrain Champion.

Champion "pulled free several times before the officers were able to take him down to the carpeted foyer," the spokesman said.

As the man struggled, a set of handcuffs were put on each hand and joined together as he lay face down. When the man began to kick violently, a cloth strap was put around his ankles. While on the floor, Champion vomited, prompting officers to call for medical assistance.

Within three minutes, emergency medical technicians arrived. The police spokesman said that Champion "did not appear to be in distress." The fire chief, however, said Champion was still vomiting and paramedics asked for the handcuffs to be removed, rolled Champion onto his back and performed CPR.

Four minutes later, an ambulance was on the scene. Champion's pulse was faint, and he was transported to the hospital and pronounced dead.

This incident received major media coverage in the Nashville area. Calls for better police training, the issues of poorly trained workers, civil rights abuses, lapses in state care, and the inevitable filing of a federal lawsuit against the police and Calvin's care agency all punctuated the city's news headlines in the weeks that followed. State mental health officials stopped sending new clients to the contract agency that was involved, pending a further investigation[8]. And all with good cause since there exists a general lack of understanding and education nationwide among not only those who respond first to predict-

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[1-8] *The Tennessean news reports from May 2-June 22, 2000.*

Law Enforcement Awareness of Autism

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able incidents that involve children and adults with autism, but often by the very industry workers who are responsible for their care.

Was Calvin Champion's Death Avoidable?

While a Nashville federal court judge or jury may have an opinion, no one will ever know for sure. But there is information, curriculum and training available to provide care workers and police a better understanding of autism, the issues of risk and misunderstanding that children and adults and their families face repeatedly, and information on approach techniques that responders and care workers can utilize to de-escalate risk situations.

Since the mid- to late 1990's autism advocates have taken it upon themselves to create informational tools that help law enforcement agencies and emergency responders better understand and respond to persons with autism. An understanding of the issues of concern to autism community families—child and adult elopement or "runners" misidentification of behaviors as "suspicious persons" by uninformed passersby resulting in 911 calls, false confession — is now considered a priority concern for many autism advocates.

The Wayne County Society for Autistic Citizens (WAY/SAC) - the Wayne County, Michigan Chapter of the Autism Society of America (ASA) published a booklet in 1994, "Avoiding Unfortunate Situations," which described and addressed the elopement and false confession issues. Law enforcement awareness has been a topic at ASA conferences since 1995, as well as other autism advocacy organizations, including the Syracuse New York-based self advocacy organization Autism Network International, state autism societies in Ohio and Wisconsin, and Autism-Europe Congress 2000 in Glasgow, Scotland.

The Harrisburg, Pennsylvania chapter of ASA released the award-winning "Autism Awareness Video for Law Enforcement/ Community Service Personnel" in 1998. The video, produced through the efforts of Judy swift, is now in use throughout the nation. The South Carolina Autism society created a curriculum and video in 1999 titled "Autism and Informed Response". Individual law enforcement professionals who are parents of loved ones with autism have embraced the training aspect of autism and are conducting training sessions in several states. Autism advocates throughout the nation are now picking up the mantle of autism education and bringing it to the attention of law enforcement agencies, criminal justice systems and legislators in their local communities.

These campaigns do work. Take the experience of Lisa Mathews as a prime example. After a brush with disaster with an eloping son, Lisa, the Maryland mother of three sons who have autism, singlehandedly began a campaign worthy of the attention of any good advocate.

In late 1998, Lisa gathered together information from the autism community about law enforcement awareness and education. She decided to start at the top level of law enforcement in the state of Maryland. After a persistent campaign of telephonic and written communication concerning autism awareness for law enforcement professionals, Governor Parris Glendenning, the state's chief law enforcer, wrote a letter of introduction for Lisa to the Maryland Police & Correctional Training Commission in Woodstock, Maryland. The Governor expressed an interest in being kept appraised of any efforts the commission might make to Mrs. Mathews request. Within three months, the commission hired Dr. Darla Rothman as a curriculum specialist. Her first assignment? Create curriculum on autism awareness.

The result is the first-ever, by the police and for the police, law enforcement curriculum on autism, "Why Law Enforcement Needs to Recognize Autism". The curriculum was released for use in late 1999 and addresses all appropriate issues for law enforcers. The curriculum is being considered for uses in other states and serves as a model for law enforcement agencies interested in training and information about current trends in policing.

If Nashville Police officers had been trained on autism issues the outcome regarding Calvin Champion Jr. may have been significantly different. If the contract agency had been trained regarding these risk and safety issues the outcome may have been better. But, according to published reports, such was not the case.

If representatives of the law enforcement and contract training agencies had undergone the training, they may have learned, among many other things, that the person with autism "may be non-verbal, may not be able to give information or able to answer questions, may not respond to a "Stop" command, may be sensitive to touch, sound, bright lights, odors, may have difficulty judging personal space; may stand too close or too fare away, may not recognize danger, may exhibit hand flapping, finger flicking, body rocking."[9a]

They may have learned that the person with autism has a "tendency to run — children with autism are prone to wander or run away at any time, may not be able to distinguish between a good stranger (police) and a bad stranger that might hurt him/her, may not understand rights, may become anxious in new situations — when stressed out, a person that normally talks well may exhibit confused speech, or become non-verbal — stress may also trigger inappropriate behaviors or bring on a seizure, may not understand consequences of actions, or the concept of punishment — has little reasoning ability, and most likely does not know what is going on."[9b]

[9a-d] *From the Maryland Police and Correctional Training Commission's curriculum, "Why Law Enforcement Needs to Recognize Autism."*

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They may have learned to "approach in a quiet, non-threatening manner, allow for delayed responses to questions, never touch or pat on shoulders or near face; avoid standing too close, (that) many are aggressive ("fight or flight reaction") if touched by strangers, evaluate person for injury; may have high tolerance for pain."[9c]

They may have learned "the first indication of an unusual situation may be through the person's behaviors (which were probably the initial reason the police were called to assist), use all available information: person's name, age, appearance, statements from bystanders, types of behaviors exhibited, avoid the impulse to act quickly, take time to assess the circumstances (time is on your side), maintain a safe distance until the inappropriate behaviors have lessened, remain alert for sudden outbursts or impulsive actions, control the situation using communication skills rather than physical skill."[9d]

While we will never know if the training would have made a different for Calvin Champion, Jr. or others with autism around the country who have had similar fates, we can only hope that it would have made a critical difference. But responsible advocates can make every effort to bring this kind of information to the attention of those in first response situations.

In Wayne County, Michigan, local chapters of the Autism Society, Alliance for the Mentally Ill, Alzheimer's Association, and Arc have banded together with the community mental health agency, law enforcement community, corrections department officials, prosecutors, emergency care and response professionals to develop a 16-hour workshop for law enforcement personnel titled, "Effectively Working with Persons with Mental Illness and Developmental Disabilities." The workshop addresses situations of risk, how to access community mental health services and supports, understanding of legal issues related to protective custody and involuntary commitment, and sensitization to the needs and experiences of persons with disabilities and their families. Veteran and rookie officers give this training high marks for usable information. Broward County, Florida has established a disabilities court held by a judge who is familiar with disability issues and thus able to make good decisions on the bench.

Law enforcement agencies in the 21st Century are becoming increasingly aware of the diverse communities that they serve. Most welcome information and advice on how to recognize and work through circumstances and situations that can become volatile. Understanding autism, the people it affects and others with serious disabilities is becoming another part of the job for law enforcement professionals.

Individuals and advocacy agencies need to develop collaborative working relationships with the law enforcement agencies that serve their communities. Once established, these relationships should bear the fruit of an increased understanding of serious disabilities and better outcomes when persons who have disabilities encounter law enforcement professionals in field situations. Public awareness and education remain our most effective weapons against misunderstanding and unfortunate situations. It is never too late to start educating others about our loved ones.

Dennis Debbaudt is a 23-year veteran of law enforcement in the private sector and the parent of a 17-year old son with autism. An active autism advocate, he has researched and reported on the issues of autism and law enforcement since 1991.

Mr. Debbaudt may be contacted by e-mail at ddpi@flash.net

Remembering Marsha Snyderman Forest

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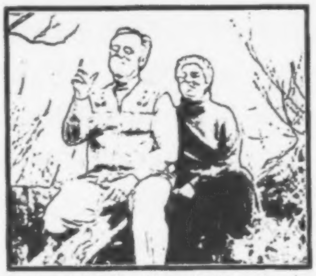
with the system that supports people with developmental disabilities. The room was packed and the atmosphere hot before she even stood to begin. Hostility. Purpose. Resentment. Determination. Anger. Hope. Rage. Will. All these things filled the air with such electricity that a bolt of lightning was the only thing that could result.

And it did. Marsha began to speak. And she was Marsha the uncompromising. Marsha the visionary. Marsha the bully. Marsha the caustic. Marsha the strong. She became the flashpoint for the room. The focus of hope. The lightening rod for anger. I had never before seen someone with such passion for what was said, such righteous determination for what must be, such dogged persistence for the change we must make. I left the session drained. And challenged. And in some remarkable way, changed. She had demonstrated that passion had a place in what we did. She showed how one person could withstand a firestorm of controversy. She defined and personified the difference that one person could make.

I would meet her again years later and learn that Marsha's last name wasn't Forest, it was Andjack. I would meet a man who loved her, with the same uncompromising zeal that she demonstrated was possible in life, whose name wasn't Pearpoint. It was Andmarsha.



Jack and Marsha (photo by Karen Levy)

Diverse City Press, with which I am affiliated, had a display booth next to Inclusion Press at a TASH conference. Here Marsha Andjack, along with Jack Andmarsha, held court. Their booth was a testimony to a life lived full of diversity and equality. Their booth wasn't a sales opportunity -- it was a community happening. Jack, for whom a peer is the point, presided over the booth and cared for Marsha with gentleness and humour. They

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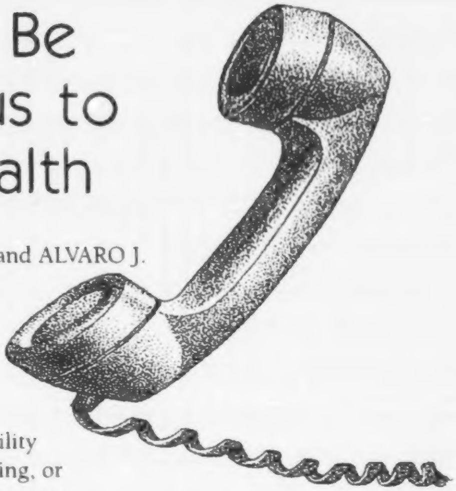
911 Can Be Dangerous to Your Health

BY BARBARA E. RANSOM and ALVARO J. MADRID



If you are a person with a disability that impairs your speech, hearing, or mobility, makes it difficult for you to follow instructions, or if your disability causes you to become unconscious or disoriented, a call to 911 may be dangerous to your health. With the closing of large institutions, more people with disabilities are living lives in the community. Advocates rely on The Americans with Disabilities Act of 1990 (ADA),[1] touted as the Civil Rights Act for people with disabilities, to facilitate this integration into the community. The ADA does require local government agencies to make programs, services and activities accessible to people with disabilities. In spite of this mandate, many local governments are negligent of their duty to protect and serve all people within their jurisdiction. When this negligence impacts on the services that a 911 call is designed to provide, the results can be deadly.

- John Jardine, a 25-year-old man, had finally gotten his seizures under control enough to enroll as an undergraduate student at Arizona State University. In March of 1999, he suffered a severe seizure. A classmate called 911. When the emergency medical team (EMT) and the campus police arrived, John, behaving in a fashion typical for people who have had a seizure, staggered about in a state of confusion and exhaustion. The EMTs tripped John and forced him onto his stomach. The campus police handcuffed him. Forty-six minutes after the onset of his seizure, John Jardine was pronounced dead at Tempe St. Luke's Hospital from suffocation.[2]

- Charles Thompson, Jr. was a 40-year-old man who developed mental disabilities following a suicide attempt at age 14. His family made a 911 call because Charles had become violent and threatening. He was armed with two machetes. Two Williamson County (Tennessee) police officers responded to the 911 call. Charles had run out of the house and hid in the woods. The officers confronted him as he came back to the house and ordered him to stop and drop the machetes. One officer who was peering around the side of the house shot Charles dead with a shotgun. The officer fired his shotgun because he believed Charles made a move to throw the machete at him.[3]

- John Washington, a 17-year-old man with autism and mental retardation, was playing in his front yard in Pennbrook, a suburb of Harrisburg, Pennsylvania. There had been several 911 calls about peeping toms in the neighborhood. As John was looking in his window, two police officers approached him. They tried to handcuff him. John screamed and tried to run inside when the officers tackled him. John suffered a dislocated shoulder.[4]

- Eric Stetter, 26, was at home with his parents on October 9, 1999. He suffered a violent seizure and his parents called 911. Two Hanover Park (Chicago area) police officers arrived first. Within minutes, two EMTs and four more officers arrived. Eric's parents repeatedly informed the officers that their son was having a seizure. Nonetheless, the officers tackled Eric, handcuffed him and taped his legs together. Several officers and the two EMTs placed Eric face down on the family's couch and knelt on top of him. Eric Stetter was pronounced dead on arrival at the hospital[5]

- Alphonse Groman, a 75-year-old man, suffered a mild stroke in February of 1990 in his New Jersey home. A neighbor made a 911 call. The Township dispatched the police and a medical team. Mr. Groman was disoriented and refused medical attention. An officer tried to force Mr. Groman into a chair; he resisted and became argumentative. Family and neighbors claimed that the officer punched him in the mouth, placed him in handcuffs and took him to the police station. While at the station, mr. Groman sustained injuries to his face and head. The police charged him with aggravated assault, disorderly conduct, and resisting arrest. He was acquitted on all counts.[6]

Deadly mistakes can occur when untrained persons respond to a 911 call. With proper training, many of these situations could have been avoided or deescalated to prevent serious physical injury and death.

911 is a Service Covered Under the ADA

The ADA regulations mandate that every government with 50 or more employees:

- Hire or assign an ADA Coordinator, someone responsible for reviewing programs, services and activities to determine their impact on people with disabilities.
- Perform a self-evaluation of all programs, services and activities to ensure that they are accessible for people with disabilities.
- Prepare transition plans for compliance with the ADA for those programs,

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911 Can Be Dangerous to Your Health

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services and activities that are not accessible with a plan for making them accessible.[7]

Although 911 is a program, service or activity within the meaning of the ADA, local governments, through their lack of compliance, have made this service inaccessible, by its inadequacy and, in some cases, by its lack of responsiveness, to people with disabilities.

In a consolidated action, three plaintiffs claimed that the Phoenix (Arizona) 911 emergency system did not respond effectively, if at all, to their TDD calls. A man with hearing loss wanted to report two suspicious strangers outside his home and used his TDD to call 911. On four separate attempts, the dispatcher disconnected his call. Help came too late to stop the prowlers from breaking into his pickup truck and driving away. A woman tried to use the TDD system to contact 911 because her father was seriously ill. It took three tries for a successful connection. Another Arizona man tried to use his TDD to call 911 because he had been burglarized. After five attempts, he still was unable to connect. Officers arrived eventually.[8]

911 Can Be Made Accessible and Safe for People with Disabilities

A 911 call, even if for a medical emergency, frequently results in police officers arriving before, with, or after the medical team. When police officers and EMTs are not trained to recognize characteristics of disabilities, they misinterpret classic behaviors of mental illness or developmental disability for criminal activity. Police officers, by training, apply the use-of-deadly-force continuum and think in terms of subduing and restraining rather than observing, evaluating and then reacting. When a lack of training and poor policies make 911 inaccessible to people with disabilities, the ADA requires that new training curricula, policies and procedures be developed and implemented. This taxpayer-financed service must be applied even-handedly so people with disabilities can receive its benefits.

Changing a system can be difficult, but it is possible. The Public Interest Law Center of Philadelphia (Law Center), a national leader in effecting systemic change, emphasizes a three-pronged strategy: Compromise, Lobby for Legislation and Litigate for Systemic Change. Sometimes, it takes all three to get the job done.

Compromise

In Philadelphia, the University Affiliated Program at Temple University has worked with the local police department to help change procedures and make 911 more accessible to people with disabilities. The UAP has worked with the department's ADA coordinator to develop a premise history form that people with disabilities or family members can complete to alert the 911 dispatcher that the call is from the home of a person with disabilities. The information is inserted into the 911 databases and the dispatcher can advise EMTs and police that there is a person with disabilities at the residence, identify the disability and any necessary accommodations. A prepared responder is less likely to act irrationally than an unprepared responder.

Lobbying for Legislation

Advocacy groups can learn from the Religious Right: combine resources to pressure for change and impact state and local governments. Applying these strategies, the Law Center and 77 other advocacy organizations in Pennsylvania formed the Coalition Advocating for Disability Rights and Empowerment (CADRE). CADRE advocates for the State's municipal police officers to receive training to recognize characteristics of specific disabilities and to respond appropriately. Twice, the House unanimously passed CADRE's proposed bill, but the Senate's "Law and Justice" Committee refused to move the bill out of committee and on to the floor.

On July 24, 2000, Governor Gray Davis of California signed Bill AB 1718 mandating that continuing education for law enforcement personnel must include training to identify indicators of developmental disabilities and mental illness and alternatives to deadly force when interacting with people with developmental disabilities and mental illness. The Bill was spearheaded by Craig A. Durfey, an advocate, and introduced by Assembly Member Hertzberg. (See the sidebar on page 35 for highlights of AB 1718.)

Litigating for Change

On February 18, 1998, Ronald Parks of Darby Borough, Pennsylvania was awakened by a gran mal seizure. His family called 911. A police officer was the first to arrive. Despite the family's protestations that Mr. Parks was having a seizure, the officer wrestled Mr. Parks to the ground. The EMTs and more officers arrived. The EMTs and the police restrained and handcuffed Mr. Parks. Ironically, the Epilepsy Foundation of Southeastern Pennsylvania had offered to conduct free training sessions for area police officers and EMTs to explain, among other things, that holding down a person in a seizure or post-seizure state is like holding a drowning man's head under water. No one from the Borough attended the sessions.

The Public Interest Law Center of Philadelphia represents Mr. Parks in his action against the 911 responders because the case is an opportunity to change a system that is desperately in need of change. The Epilepsy Foundation accepted the invitation to be a party to the solution.[9] In a partial settlement, the State agency, one of the defendants, has included representatives from CADRE on a Panel to develop a unit in the police training curriculum to prepare officers to recognize behaviors of people with disabilities and to rely more on common sense and less on deadly force in their interactions with people protected by the ADA.

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911 Can Be Dangerous to Your Health

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Strong Advocacy Organizations Can Change Weak 911 Systems

When litigating for change, the Law Center seeks strong organizational plaintiffs to join in the effort. Organizations do not abandon a suit solely for a monetary settlement. Little wonder that defendants challenge the right of an organization to be a plaintiff. This challenge can be defeated if the organization meets the requirements set by the courts: 1) its members would otherwise have a right to sue in their own right; 2) the interests the organization seeks to protect are germane to its purpose; 3) the organization has a history of using its resources to support this issue on other occasions; and, 4) neither the claim asserted nor the relief requested require the participation of individual members.[10]

On August 28, 1999 and June 12, 2000, Brad McArthur, a 30-year-old man with autism and mental retardation, was beaten by Harrisburg police responding to a 911 call about a prowler. Neighbors tried to stop the beatings by telling the officers that Brad had disabilities and that he never harmed anyone or anything. The officers beat Brad about the face and head. He was hospitalized for 5 days because the trauma to his head resulted in seizures. The ARC of Pennsylvania and the Autism Support and Advocacy Program are the organizational plaintiffs. They are intent on forcing the issue of police preparation and training through this case.

911 Must be Responsive to People with Disabilities

Local governments must ensure that their 911 services comply with the provisions of the ADA. People with disabilities are hurt and killed by a 911 service that should be available for all even handedly. Advocates and Self-advocates must ensure that other states follow the example set by Governor Davis and the California Assembly. Further, they must mobilize their organizations to take on the challenge through the courts when necessary.

Endnotes

[1] 42 U.S.C. Subsec. 12101-12134, as implemented by regulation at 28 C.F.R. Part 35.

[2] *Jardine v. City of Tempe*, et al., CV-99-20660, (Super. Ct. of Maricopa County, AZ 1999)

[3] *Thompson, et al., v. Williamson County, et al.*, 2000 WL 973414 (9th Cir. 2000).

[4] *Washington, et al. v. City of Harrisburg, et al.*, 95-CV-01437 (W.D. Pa. 1995).

[5] *Stetter, et al. v. Village of Hanover Park, et al.*, 99 C 7084 (N.D. Ill., Eastern Division, 1999)

[6] *Groman, et al. v. Township of Manalapan, et al.*, 47 F.3d 628 (D.N.J. 1995).

[7] 28 C.F.R. Subsec. 35.105, 35.106, 35.107(a) and 42.505.

[8] *Ferguson, et al., v City of Phoenix, et al*, 157 F.3d 668 (9th Cir. 1998).

[9] *Parks, et al. v. Darby Borough, et al.*, 99-CV-3810 (E.D. Pa. 1999).

[10] Herbert B. Newberg et al., Newberg on Class Actions Sec. 6.03 (3d ed. 1992) (citing Hunt v. Washington State Apple Comm'n, 432 U.S. 333 (1977)).

Barbara Ransom is a member of the TASH Executive Board and an attorney with the Public Interest Law Center of Philadelphia (PILCOP). Alvaro Madrid is a 2nd year law student at Temple University School of Law and a summer intern at PILCOP.

Comments concerning the information contained in this article may be directed to Ms. Ransom at justice@vcsn.com

California Requires Its Police Officers to Receive Training in Disability Awareness

On July 24, 2000, Governor Gray Davis signed Bill AB 1718. This law establishes training for California's police officers in disability awareness. AB 1718 requires that, on or before June 30, 2001, California's Commission on Peace Officer Standards and Training establish and keep updated a continuing education classroom training course relating to law enforcement's intervention with persons with developmental disabilities or mental illness, or both, as specified. The course is to be developed in consultation with community, local, and state organizations and agencies that have expertise in the area of mental illness and developmental disability, and with appropriate consumer and family advocate groups.

The training courses must teach officers all of the following:

(1) The cause and nature of mental illnesses and developmental disabilities.

(2) How to identify indicators of mental illness and developmental disability and how to respond appropriately in a variety of common situations.

(3) Conflict resolution and de-escalation techniques for potentially dangerous situations involving mentally ill and developmentally disabled persons.

(4) Appropriate language usage when interacting with mentally ill and developmentally disabled persons.

(5) Alternatives to lethal force when interacting with potentially dangerous mentally ill and developmentally disabled persons.

(6) Community and state resources available to serve those with mental illness and developmental disabilities and how these resources can be best utilized by law enforcement to benefit the mentally ill and developmentally disabled community.

FREEDOM • CITIZENSHIP • FUNDING
The First International Conference on
Self-Determination
& Individualized Funding

"Funding, Freedom and Citizenship": The First International Conference on Self-Determination and Individualized Funding

Seattle, Washington, U.S.A.
July 29-31, 2000

Over 1240 people, including people with disabilities, family members, community advocates, professionals, service providers, researchers, administrators, and government officials from 22 countries around the world and all fifty of the United States participated in this ground-breaking event. Our heartfelt thanks go out to members of the organizing group and conference committee, and especially to Steve Dowson and Brian Salisbury who co-chaired the program planning committee and put together an agenda that was diverse, incredibly motivating and extremely informative.

The conference was rich in opportunity and outcomes, with topics and speakers broad enough to encourage participation from a range of disability areas including developmental disability, the independent living movement, seniors, and people involved in the mental health movement.

The conference took place at an important point in the broader disability movement, as there is an increasing focus on the need to secure real citizenship opportunities for people with disabilities. In support of this, many individualized funding programs are now operating, being planned or being put into action. While this is truly exciting, there is also the risk that the real aim -- citizenship for all -- will be forgotten, and that programs which claim to be individualized funding will really be no improvement on the systems which operate now. With a view to keeping these developments "on track," conference organizers developed a process to produce and disseminate a ***Declaration*** that will identify a set of general principles which can shape how stakeholders across programs, groups, states and nations think about and implement these ideas.

With over 1200 people in attendance, it seemed unlikely that all would agree on the ideas for the ***Declaration*** without some help. Three small groups were convened to work on the ***Declaration*** throughout the conference. These groups were called Prospector Groups because, like prospectors dipping sieves in streams as they mined for grains of gold, they were engaged in a process of searching for the special grains of truth that needed to be incorporated into the ***Declaration***. They did this by making presentations and receiving feedback, attending others' sessions and listening, and seeking out conference participants to get their views.

Credit and commendations go to the following people who worked tirelessly as prospectors: Laurie Powers, Jackie Downer, Michael Bleasdale, Michael Bach, Chester Finn, Jackie Maniago, Bruce Uditsky, Rocky Rothrock, Jane Tilley, Sue Swenson, David Martin, Alicia Contreras, Judi Chamberlin, Theresa Rankin, Jackie Golden, Phillip Ripper, Roger Jones, and Tim Stainton. Thanks also to David Towell, Facilitator; David and Faye Wetherow, Graphics; and David Weins, Technical Support!

WELCOME TO THE
FIRST INTERNATIONAL
SD/II CONFERENCE

THE SEATTLE 2000 DECLARATION ON SELF-DETERMINATION & INDIVIDUALIZED FUNDING

This conference has been founded on the certainty that people with disabilities have the same rights as other citizens to freedom, equality, equal protection under the law, and control over their own lives. These rights must be honoured if people who have disabilities are to be fully included as valued citizens in the relationships and opportunities of community life.

Many people require personal supports or other services to ensure their full citizenship and inclusion. These supports and services must be funded and provided at a level and in ways that uphold the rights of the individual.

This conference is no less certain that these rights have often been disregarded. Citizens who have disabilities experience oppression in many aspects of their lives. The causes of oppression include poverty, other people's attitudes, and the systems of publicly and privately funded support services, comprising:
* laws, policies and regulations;
* state and private sector funding bodies;
* agencies which provide services.

These systems operate in ways that deny control to those they are intended to serve. Without accountability to those who require their assistance, these systems decide how, where and with whom people shall live and spend their days. While this situation persists, people of many nations will not be able to exercise their rights or fully participate in their communities. For these reasons,

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"Funding, Freedom and Citizenship": The First International Conference on Self-Determination and Individualized Funding

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this conference calls on policy makers in all countries, at all levels of government, and on agencies which provide support, to ensure that the assistance made available to all citizens is based on the following principles:

Self-determination: founding principles

1. Self-determination for people with disabilities must be the founding principle of public policy.

2. Legislation to promote self-determination or individualized funding must be grounded in the principles of human rights and social justice.

3. Self-determination is a birthright which must be upheld by government. It is not a commodity to be delivered by services.

4. All people, including individuals with disabilities, have rights and responsibilities to live as full citizens. The barriers that stand in the way must be eliminated.

5. The development and implementation of policy must take account of the interdependence of the individual; others with disabilities; the community; and government.

6. Policy and practice must acknowledge and honor risk-taking as an essential element of self-determination and an important part of life.

7. Demands that individual self-determination should only be allowed when certain standards are met must be rejected.

8. The many contributions made by people with disabilities, which include innovation, problem-solving, improvements in accessibility, and other contributions to humanity, must be recognized.

Action required to support self-determination

9. People with disabilities speak from personal experience, and so with authority and expertise. Their views should be valued, and not regarded as having less importance than those of professionals.

10. People with disabilities and their families must be present and central at all planning and decision-making tables in policy development.

11. Citizens with disabilities and their supporting networks and organizations must be in charge of developing and promoting public policy which is related to the provision of supports.

12. Policy must be designed and implemented to ensure the inclusion of people who are at the risk of exclusion or disadvantage on the basis of ethnicity, culture, gender, race, religion, sexual orientation or other grounds.

13. Negative, entrenched attitudes, both within and beyond services for citizens with disabilities, must be addressed.

14. An understanding of disability as a consequence of society's organisation and other people's attitudes (the 'social model') rather than the inevitable result of the individual's impairment (the 'medical model') must be promoted.

15. Other citizens must be encouraged and educated to recognize that people with disabilities are entitled to access, accommodation and supports; and that individualized funding is the best way to target supports that meet peoples' needs.

16. Governments must require that public funding is used to create systems which support self-determination. Such systems will be characterised by innovation, a focus on results, and employ people with disabilities and their families.

Individualized funding: Guiding principles

17. Individualized funding arrangements must allow for flexible practice within consistent guiding principles.

18. Individualized funding and planning systems must be flexible and responsive to the culture, values and preferences of each person and their family.

19. People must not be required to give up their right to acquire income and personal assets in order to access public funding for disability supports.

20. There must be universal access to funding and support, within a range of individual need which must be defined through a collaborative process.

21. Individual funding systems must include arrangements to provide assistance, where required, in the management of funding and supports, and not limit eligibility on the basis of judgements of 'capacity.'

22. The design of individualized funding systems must reflect the reasonable assumption that recipients are trustworthy.

23. Individualized funding must be recognized as a means to honor people's vision for the future.

24. Individualized funding must be recognized for its value as an investment in people and communities.

Individualized funding: Principles for implementation

25. The funding allocated to each person should be based on their individual need, not on pre-defined and arbitrary limits.

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"Funding, Freedom and Citizenship": The First International Conference on Self-Determination and Individualized Funding

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26. Individuals must be free to pay the providers of their choice, including family members.

27. Individuals must have full control over their supports, including the planning of supports, and choosing and directing their support providers.

28. People must have a choice of budgetary and administrative support services to assist them in using and tracking their individualized funding.

29. People must be given the opportunity and support to explore options and make their own choices of sources for forms of assistance such as brokerage, advocacy, and peer support.

30. Service providers and agencies must be encouraged to endorse and apply the principles of self-determination and individualized funding; and, in an expanded organizational role, to deliver supports that minimize dependency and strengthen partnerships with the larger community to address barriers to freedom and opportunity.

31. Individualized funding systems, support services, and technical assistance services must be designed and provided so as to ensure that their forms of communication, physical and environmental characteristics, and overall quality do not undermine their accessibility.

32. Individualized funding arrangements must be straightforward and easily understood by everyone.

33. Action must be taken to encourage the recruitment and employment of people with disabilities in the administration of individualized funding systems.

Individualized funding: Evaluation

34. When the success of Individualized Funding is assessed, the evaluation must take due account of the improvements in quality of life, and in particular the extent to which personal choice, control and sense of belonging are enhanced.

35. When proposed or implemented individualized funding systems are compared with block-funded services, it must be recognized that block-funded services have not been generally successful, either in terms of the efficient use of public funds, or in the quality of life provided to the people who received the services.

❖ ❖ ❖

Here are some of the things attendees liked the most about the conference:

◊ The people, the presenters, planners and participants from all over the world here to talk about and further work and a common value! Incredible
◊ Listening to different accents in sessions!
◊ The evening of theatre!
◊ Cross-Disability reference
◊ The creation of the Declaration
◊ Flexibility in making it work (ie: opening airwalls, moving chairs and rooms)
◊ Meeting and getting to know self-advocates from around the world
◊ Talk of the town- hearing personal stories was the best part- we need to listen more to self-advocates!
◊ Good international representation
◊ Excellent workshops and information

A final report of the conference proceedings will be available and sent to all registrants of the conference about two months following the conference. Check the website http://members.home.net/directfunding/ for more updates and to see pictures presented as part of a fantastic finale by P. Sue Kullen from Baltimore, Maryland.

Many thanks to the following supporting and sponsoring organizations that assisted over 70 family members and people with disabilities from all over the world to participate in this conference:

FOUNDING ORGANIZATIONS:

○ TASH - Disability Advocacy Worldwide
○ British Columbia Coalition for People with Disabilities - CANADA
○ Administration on Developmental Disability - USA
○ Canadian Association for Community Living - CANADA
○ The Arc of the United States -USA
○ American Association on Mental Retardation - USA
○ National Program Office on Self-Determination - A Robert Wood Johnson Foundation Program - USA
○ Self Advocates Becoming Empowered - USA
○ Inter-American Institute on Disability- USA

Sponsoring Organizations:

○ Glendale Foundation for Research and Community Support - USA
○ The Center on Human Policy - USA
○ British Columbia Paraplegic Association - CANADA
○ British Columbia Association for Community Living - CANADA
○ The Presidential Task Force on Employment of Adults with Disabilities - Washington, DC- USA

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"Funding, Freedom and Citizenship": The First International Conference on Self-Determination and Individualized Funding

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- World Institute on Disability - California -USA
- The Alliance for Self-Determination - Oregon - USA

Supporting Organizations:

- CARF . . The Rehabilitation Accreditation Commission-USA
- Langley Association for Community Living - British Columbia, CANADA
- Community Living Society - British Columbia, CANADA
- VELA Microboard Association - British Columbia, CANADA
- MSA Society for Community Living - British Columbia, CANADA
- People First of Washington - Washington State, USA
- Planned Lifetime Advocacy Network - British Columbia, CANADA
- The Arc of Washington State - Washington State, USA

- Washington Initiative on Supported Employment - Washington State, USA
- Greater Vancouver Community Services Society - British Columbia, CANADA
- Speaking for Ourselves - USA
- Values Into Action - ENGLAND
- Central England People First - ENGLAND
- Community Living Journal - ENGLAND
- Lifeworks Services - Minnesota, USA
- The National Parent Network on Disabilities - USA
- Inclusion International - FRANCE
- Kirinari Community Services - AUSTRALIA
- Elizabeth M. Boggs Center on Developmental Disabilities - The University Affiliated Program of New Jersey, Robert Wood Johnson Medical School / University of Medicine and Dentistry of New Jersey - USA
- Justice for ALL - Washington, D.C., USA
- Maryland Association of Community Services - USA

All photos courtesy of P. Sue Kullen.

Remembering Marsha Snyderman Forest

August 15, 1942 - June 2, 2000

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were, and will always remain in my mind, a couple.

As Marsha grew ill, she and I began a series of letters to one another about life and death. One of the issues that was left unresolved came from those days of fiery rhetoric and battles fought. She had come through, not unscathed as I had thought. In my mind it was impossible to think of Marsha's spirit made of anything but the hardest steel. I was wrong. She fought the good fight but was left wounded. She knew that some people could only see her as the angry woman with a cause. The uncompromising rebel. The Inclusion Witch.

One conversation that we had, told me of a pain that she carried with her. "Why won't people let you grow?" she asked me one day. "Why do they insist on putting you in a box and thinking that you don't develop, change, mature?" She knew at an instinctive level that there were those whose opposition to her and her belief that ALL MEANS ALL called her both a caustic and vitriolic woman. "Men are called passionate, women are called names," she said to me while discussing this issue.

But people had slowly begun to realize that Marsha led a fight that needed a Warrior Princess. And she was that warrior. Only a week before she died, Marsha and Jack attended the Ontario Association for Community Living award dinner. At that dinner they received a lifetime achievement award. There they were surrounded by Ontario -- the movement. There they found themselves loved, admired and honoured. Marsha confided in me the day after the award that the statue was beautiful, but that the sentiment it represented was healing for her. It was as if the entire movement in the room that day had layed their hands on Marsha's spirit and wished it well on its journey into the future. Her spirit soared even as her body failed. She had been blessed to have had a vision. To have led a movement. To have taken her place in history -- an immortal whose name will never be forgotten. A week later she had died. Peacefully. Knowing full well that we had caught up with her and had understood her passion. She had always included us, but now we had included her. She had fought valiantly and had died gently.

Marsha Forest believed. And because she did a little child with Down Syndrome boards a bus to go to school. Part of the crowd. Part of the school. Part of real life. Rest well Marsha Forest. You've earned rest. Be well, Jack -- our hearts are with you.

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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( ) Early Childhood Services
( ) Educator/Teacher (K-12)
( ) Government Personnel
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional/Public Policy Advocate
( ) Professor/Instructor-College/University
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
( ) Student
( ) Supported Employment
( ) Other

Moving? ***Please notify TASH of your new address.***

General Membership (individual)	$103*.
Organization/Subscription (all organizations, schools, libraries, universities, etc. must use this category)	$230*.
Associate Membership (for people having an annual household income of $25,000 or less, and for whom payment of the full fee would present a financial hardship)	$60*.
Lifetime Member	$1000.

Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

Group Discount Rate (When three or more individuals from the same organization join as International/Chapter or International Only members at the same time -- Save $20 per membership!)

Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information in the next column:

( ) Mastercard ( ) Visa ( ) Discover

Card Number____________________Expiration Date________

Signature____________________________________

( ) I would like to spread my payments out. Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone:410/828-8274 Fax: 410/828-6706

*These prices are for both International and Chapter memberships. For International-Only or Chapter-Only rates, please call us at 1-800-482-8274.

TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204
Phone: 410/828-8274,
FAX: 410/828-6706,
TDD: 410/828-1306
Web site: www.tash.org

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URGENT!
Dated Material Inside!
2000 TASH Executive
Board Election Ballot!

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U.S. POSTAGE
paid
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PERMIT# 187

AUGUST 2000

PRINTED IN THE U.S.A.

TASH Newsletter

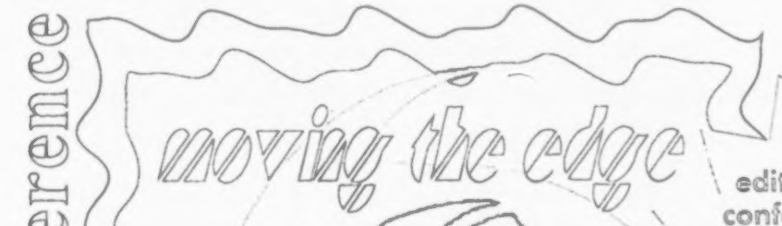
VOLUME 26 ISSUE NUMBER 9 SEPTEMBER 2000

2000 TASH Conference

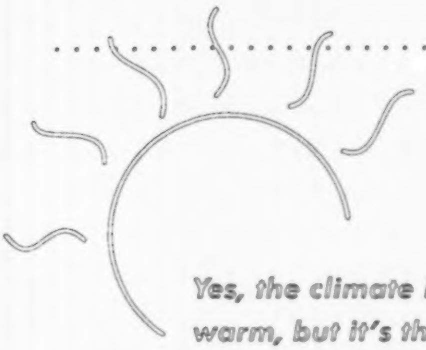
"Moving the Edge"

December 6-9, 2000

Fontainebleau Hilton Resort and Towers • Miami Beach, Florida


2000 TASH Conference
moving the edge
Miami Beach, Florida - December 6-9th

This special edition is a tentative conference agenda as of September 1, 2000. Alternate formats are available on request. Este Folleto está disponible in español.

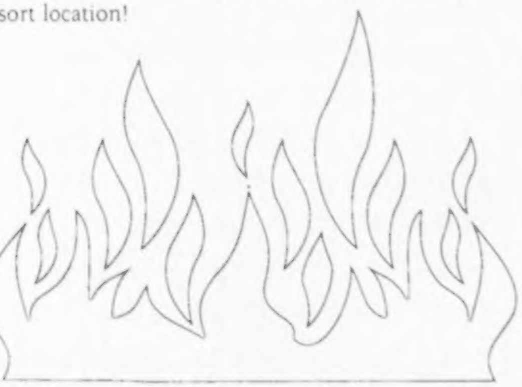


Yes, the climate is warm, but it's the TASH Conference that will really be heating things up in Miami Beach this December! Plan to join us for the internationally recognized TASH Conference, "Moving the Edge."

The fabric of diversity and inclusion is made up of many threads, and the TASH Conference is known for being a well-woven gathering of people who are passionate about the rights of every individual with a disability. TASH members, in collaboration with their families, friends, and colleagues around the world have been paving the way and stretching the boundaries for what is considered "the cutting-edge" in supporting people with disabilities to live the lives of their choice for over 25 years.

This silver anniversary conference will feature ways to move that edge even further, with 14 full-day pre-conference events, 38 topic specific breakout strands covering the full spectrum of issues affecting people with disabilities and their families, over 80 exhibits, a networking luncheon, and new this year – an exclusive poster session featuring poster presentations from around the world!

For the second year in a row, Miami Beach has been named the Top Urban Beach. Bring the entire family to the conference, and enjoy this world-renowned resort location!



Sí, el clima es caluroso, pero es la Conferencia de TASH la que verdaderamente estará poniendo al rojo vivo las cosas en Miami Beach este Diciembre! Planea asistir a la internacionalmente reconocida Conferencia de TASH, "Avanzando hacia un futuro sin barreras".

Es la estructura de diversidad e inclusión que se ha llevado a cabo a través del apoyo de grupos y personas de grupos diversos, por lo que la Conferencia de TASH es reconocida por ser una convivencia de personas apasionadas de los derechos de las personas con discapacidad. Los miembros de TASH, en colaboración con sus familias, amigos, y colegas, alrededor del mundo han venido cimentando la manera y han ido mas allá de las fronteras de lo que es considerado "la única opción positiva y autentica" en cuanto al apoyo a personas con discapacidad para que vivan su vida de la forma que ellos lo deseen y escojan durante más de 25 años. Este folleto está disponible en español. Para mayor información, por favor llame al 1-800-482-TASH o escribanos a information@tash.org.

2000 TASH CONFERENCE
The Fontainebleau Hilton

○ Miami Beach, Florida ○ December 6–9, 2000

Travel Discounts

ATC MEETING PACKAGE INCLUDES:
- AIRLINE DISCOUNTS up to 15% off the lowest available fares*
- CAR DISCOUNTS: special convention rates—ask your agent
- ZONE FARES region–to–region flat rates
- CONSOLIDATOR AND NET FARES reducing the cost of high price tickets
- NEW TRIP MANAGER: on-line reservation system
- NEW POWER PRICING: computer software search for the best fare on all airlines
- NEW RESFAX: fax back service with 36 options and prices for your requested travel times

ATC EXTRAS:
- Advanced seat assignments
- NEW Website that includes on-line reservations, maps, city and travel links
- Special meal requests
- Frequent flyer mileage updates
- Personal Profiles for repeat and TRIP MANAGER customers

○ **ASSOCIATION TRAVEL CONCEPTS**
Phone 800 458 9383
Fax 858 581 3988
Email reservations@assntravel.com

○ American	800-221-2255	60D0UI
Alamo	800-732-3232	643284GR
Avis	800-331-1600	J952872

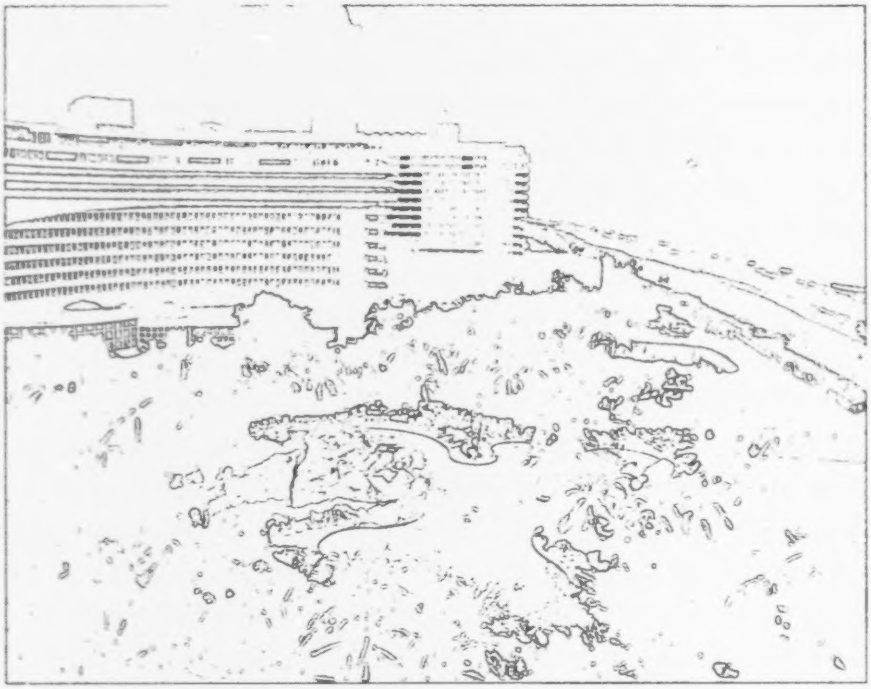
ATC

Discounts apply: 12/1/00–12/12/00

* Tickets purchased at least 60 days prior to departure receive 10% off coach and 15% off first class. Tickets purchased less than 60 days prior to departure receive 5% off coach and 10% off first class.

○ NEW WEBSITE www.assntravel.com

GENERAL INFORMATION



After a long day in exhilarating meetings, attendees can relax and network in the resort's tropical paradise. Miami Beach beckons with its perfect year round climate, beautiful ocean, sand, and endless sun. All conference related activities take place at the headquarter hotel, The Fontainebleau Hilton Resort and Towers.

4441 Collins Avenue,
Miami Beach FL 33140
Telephone 1-305-538-2000
Reservations – 1-800-548-8886
www.hilton.com

Approved 2000 Conference Rates at the Fontainebleau Hilton

Be sure to mention that you are making reservations for the TASH Conference to take advantage of these reduced rates.

Single Room - $140.00
Double Room – $160.00
Additional Person $20.00

The Hilton Family Plan allows children, regardless of age, to stay at no charge, when they occupy the same rooms as their parents. Families who include more than 4 people can request a roll away bed in the room for an additional person when they check-in, or they can request a suite, at 20% discount for the TASH Conference.

Please be advised that this does not include current room tax, which is 12.5%. The block of rooms held for the TASH Conference is being held until November 6, 2000. When the block is full, or after November 6th, rooms will be available if space permits.

Check-in at the hotel is 3:00 PM on the day of your arrival. Please make your reservations early to ensure a room!

Airline Travel

See Advertisement on page 2

Airport Shuttle

SuperShuttle is the largest airport ground transportation system in the United States, and is the preferred vendor from the airport to the Fontainebleau. SuperShuttle operates 24 hours a day, and it is not necessary to make reservations when traveling from the airport to the Fontainebleau Hilton. Simply proceed to the lower level and see a SuperShuttle Customer Service Representative at the Van Service Kiosk. SuperShuttle has 11 vans that operate, 3 of which are accessible to wheelchairs. The cost is $11.50 per passenger, each way. For specific information contact 1-800-262-5501 or 305-871-2000.

For a listing of services for accessible transportation in Miami, personal assistant services, and medical equipment rental information, please call TASH at 1-800-482-8274 or check the website at www.tash.org

Area information

To obtain a brochure of Miami, contact the Greater Miami Convention and Visitors Bureau 888-766-4264 or www.tropicoolmiami.com

Conference Registration

To avoid delays and to ensure a smooth registration, please fill out the form completely. Registration is also available over the internet at www.tash.org. A confirmation letter will be sent approximately two weeks after receipt of your registration. All materials will be provided when you arrive at the registration area at the conference site. Please note the date and times for conference registration on the tentative agenda, page 5 of this newsletter.

Childcare/Youth Activities

This year there are a variety of programs available at the conference for kids! TASH will be operating the highly successful and fun childcare program for children ages 1 month – 13 years in cooperation with KiddieCorp as we have done in years past. The charge is $2.00 per hour per child, and there is a 3 hour minimum block. Pre-registration is required. If you are interested in information about this program, please check the box on the registration form or call 1-800-482-8274.

In addition, the Fontainebleau has an extensive Resort Activities Program for children ages 5-12 and teens 13-17, who are able to swim without the assistance of a flotation device. Rates vary with activities. For more information contact the Kid's Corner at the Hilton , (305)538-2000 x 3445.

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

From the Executive Director

BY NANCY WEISS

What do you think of when you think of the annual TASH conference? Inspirational sessions? Great networking opportunities? A chance to meet people from all over the world who agree that children and adults with disabilities have a right to participate fully in all aspects of life? What about beach umbrellas, a long walk along one of the most beautiful shorelines in the United States and great tropical nightlife??

This year's conference in Miami offers the best of the stimulating opportunities we have come to expect of TASH conferences, along with a heaping helping of the new, unique and exciting. This year, just when the winter is beginning to seem as if it will never end, join new and old colleagues and friends from across the country and around the world at what is indisputably the most exciting disability conference offered. Whether this will be the most recent of many compelling TASH conference experiences or your first opportunity to attend, we guarantee you will leave renewed, excited, and armed with new ideas for effective advocacy and progressive supports.

TASH's mission statement begins with the statement, "Stretching the boundaries of what is possible...". This year's conference them takes this idea a step further. "Moving the Edge" implies that it is no longer enough to be on the cutting edge. Tash is committed to consistently looking ahead and setting a brisk pace toward assuring full and meaningful lives for all people with disabilities and their families.

This conference edition of the Newsletter is meant to wet your appetite and give you a taste of what the conference in Miami will have to offer. This year marks TASH's Silver Anniversary. Come celebrate twenty-five years of change and a future of progress as we continue to move toward a society hallmarked by diversity, opportunity and justice for all.

Whom Do I Contact??

☐ **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org

☐ **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org

☐ **For questions about the 2000 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org

☐ **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org

☐ **For information on governmental affairs, call:** Dan Dotson, Coordinator of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:ddotson@tash.org

☐ **For information on marketing and promotions, permission and reprints, newsletter submissions and advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org

☐ **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu

☐ **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

Conference Features

You spoke up.....and we listened!

The conference planning committee has made some exciting changes for this year's conference. In response to the feedback received on the conference evaluation forms, **TASH will be reducing the overall number of breakout sessions to offer a more "manageable" day of choices**. The review board will be working harder than ever to select proposals that offer the best quality presentations representing the greatest variety of interest areas. This year, you can expect to see the same great quality and variety but much less repetition.

This year the conference includes two meals. On Thursday, the conference agenda has a scheduled lunch break so that for only $10.00 extra, all presenters and attendees can attend a luncheon amidst the palm trees on the Grand Lawn. This special luncheon features roundtable discussions in a variety of topic areas. This event provides a great opportunity to discuss issues of interest with other TASH members as you enjoy your lunch with a lovely view of the beach, boardwalk and pool.

In addition, on Saturday during the exclusive exhibit and poster time, continental breakfast will be served. And, be sure to attend the Gala Reception/Silent Auction on Friday evening, as light fare will be featured, along with a cash bar.

The following topic areas will be listed as "strands" within the conference program. A strand is a series of sessions in a particular topic area, which have a similar focus, and which feature cutting-edge information and ideas. All sessions in a strand are scheduled in the same room. Strand descriptions can be found starting on page 10 of this Newsletter. 2000 Conference Strand topics include:

Advocacy
Autism
Aging
Assisted Suicide
Community Living
Criminal Justice
Early Childhood
Employment
Family
Governmental Affairs
Guardianship Alternatives
Inclusive Education Strands
- Alternate Assessment
- Best Practices
- University/College
- Communication Support & Curriculum Design
- High School Inclusion
- International Inclusion
- Literacy
- Standards Based Reform & Assessment
- Urban Issues
- Whole School Change

Leisure and Recreation
Literacy
Multicultural
Paraeducator/Paraprofessional
Personnel Preparation *(includes Distance Education and Higher Education)*
Positive Approaches
Related Services
Research
Self-Determination
Sexuality
Spirituality/Peace
Special Health Care Needs
Students Who Severely Challenge the Schools but who do not have labels of "Severe Disabilities"
Teacher Preparation
Transition

Additional sessions in the above mentioned topic areas may be scheduled at other times outside of the strand. There will be many more topics featured as well, such as management, creative and performing arts, communication, assistive technology and much more!

You will not find another conference on disability issues that has the breadth and depth of topic areas, and the incredible melding of perspectives. Plan to join us!

TENTATIVE CONFERENCE AGENDA

Tuesday, December 5th
7:00 PM – 9:00 PM

Wednesday, December 6th
7:00 - 10:00 AM Registration Open
9:30 AM - 4:00 PM TASH Techs
3:00 - 7:00 PM Registration Open
5:00 PM - 7:00 PM Opening Reception

Thursday, December 7th
7:00 AM - 10:00 AM Exhibitor set up
7:00 - 2:00 PM Registration Open
8:30 - 10:00 Opening Plenary
10:00 - 12:45 Exhibits open
10:30 - 12:45 Sessions
1:00 - 2:15 Roundtable /Box Lunch on the Grand Lawn
2:15 - 5:45 Sessions
2:00 - 6:30 Exhibits Open

Friday, December 8th
7:00 - 12:00 Registration open
8:00 - 10:15 Sessions
10:00 - 7:00 Exhibits Open
10:30 - 12:00 General Session
12:15 - 5:00 Sessions
5:00 - 7:00 Gala 25th Anniversary Reception w/ Silent Auction in Exhibit Hall

Saturday, December 9th
7:30 -10:30 AM Exhibits
7:30 -10:00 AM Posters w/Continental Breakfast
10:30 - 1:15 - Exhibit Hall Breakdown
10:00 - 1:30 Breakout sessions

Your registration includes:

- All conference sessions, events and discussion groups
- Official Conference Program - to be distributed on-site with your registration materials
- Admission to the Opening Reception on Wednesday, December 6th from 5:00 - 7:00 PM
- Admission to the Exhibit Hall
- The opportunity to attend the networking Box Lunch on the Grand Lawn, Thursday, Dec. 7th 1:00-2:15 PM for only $10.00
- Admission to the Gala Reception and Silent Auction on Friday, December 8th 5:00-7:00 PM
- Continental Breakfast while browsing the exhibits and poster sessions on Saturday, December 9th 7:30-10:30 AM

General Session
Thursday, December 7th

FEATURED KEYNOTE SPEAKER

Pat Mirenda

'The Tiles Won't Stick Without the Grout'
This keynote will employ the image of a mosaic to examine the changes that have occurred over the past 20 years with regard to the places in which people labeled with severe disabilities live, work, play, and go to school. As the "tiles" of the mosaic change from segregated to community settings, the role of the "grout" that holds them in place is often misunderstood or overlooked. In particular, the roles of augmentative communication, literacy, and positive behaviour supports as key elements of the "grout" that is essential to the integrity of the mosaic will be explored in detail. Pat is an Associate Professor in the Department of Educational and Counseling Psychology and Special Education at the University of British Columbia. Prior to this, she was the Director of Research and Training for four years with CBI Consultants, a group that provides training and support for people with severe communication and/or behaviour challenges. Dr. Mirenda lectures widely and teaches university courses about inclusive education, augmentative communication, autism, and supporting students with problem behaviour in schools. Her current research includes studies in the areas of positive school-wide discipline practices, computer technology for students with autism, and interventions for young children with autism spectrum disorders.

Also featured at this session:

- A presentation by Dohn Hoyle and Joanne McKeown on Civil Rights, Self-Determination, and Decision-Making vs. Guardianship
- 2000 TASH Awards
- Presentation of "The Key to the City" by Mayor Neisen O. Kasdire, City of Miami Beach

General Session
Friday, December 8th

FEATURED KEYNOTE SPEAKER

Dr. Oscar Arias

TASH is privileged to welcome Nobel Peace laureate, Dr. Oscar Arias, to join us in Miami as one of our keynote speakers at the annual conference. Dr. Arias is a visionary leader in the international community—promoting the organizational values reflected in the TASH Resolution on Peace. Dr. Arias is also one of the primary authors of the Nobel Peace laureates' International Code of Conduct on Arms Transfers.

Dr. Arias' keynote will provide guidance to our membership as he responds to our newly adopted Resolution on Peace and highlights the work ahead for TASH. To quote further from Dr. Arias: "*world leaders must make human security the priority for the 21st century. In contrast to the traditional concept of security linked to military capacity and economic power, human security represents the degree to which human beings are protected from ignorance, sickness, hunger, neglect and persecution. Until the demands for human security are met, discord will continue to boil in all regions of the world, periodically escalating into violent confrontations.*"

Also featured at this session:

- A Special Tribute to Marsha Forest. Though Marsha's spirit has moved on, she continues to lead us all on the journey to inclusive living.
- Contributions by Liz Obermayer, who will speak to the role individuals with disabilities have played in the current progress and the future direction of TASH.

TASH TECH Pre-Conference, Full- Day Workshops

Wednesday, December 6, 2000
The Fontainebleau Hilton, Miami Beach, Florida
9:30 AM – 4:00 PM

Plan to arrive in time to attend one of the highly informative and practical pre-conference workshops. TASH TECH workshops are interactive, and contain information that will redefine the edge in "cutting-edge" strategies for supporting people with disabilities to live, work, and play as meaningful members of their home communities. Be sure to choose early, as sessions do fill up quickly! Rates are listed on page 2 of the registration form.

T-1 Movin On: Movement Differences and Behaviors That Challenge Us

Anne Donnellan, Martha Leary

Building on the Keynote Presentation at the 1999 TASH Conference in Chicago, this session will present movement differences, the reported and observed experiences in sensory, motor, thinking and emotional differences. The contribution of these differences to challenging behaviors, communication, and learning difficulties will be addressed. A framework for personalized support, including accommodations will be discussed.

T-2 Love, Sex, and Relationships: The Journey to Joy for People with Developmental Disabilities

David Hingsburger

In this session participants will discuss the components of healthy sexuality as they apply to people with disabilities. The skills and abilities that people with disabilities need in order to live well in their bodies and in their relationships will be explored. The afternoon session will be a fast and fun look at the Facts and Myths of sexuality for people with developmental disabilities. The presenter will use sexual language and sexual humor. Warning: This is not a Value Free Workshop. The presenter will discuss the roles of values and morals within the framework to sexuality education and training.

T-3 Civil Rights, Self-Determination and Decision Making vs. Guardianship

Dohn Hoyle, Sally Burton-Hoyle, Kathleen Harris, Tom Nerney, Mayer Shevin

Stripping people of their rights by establishing guardianship is altogether too common. This workshop will focus on alternatives and best practices for supporting people at risk, including individuals with the most significant decision-making support needs. Discussion will include: how guardianship increased the risk for persons who are the most vulnerable, supporting choice and self-determination rather than substitute or "second party "best interest" decision-making, as well as best practice in keeping with TASH values. This session is designed for family members, attorneys, care management, agency staff, and long term advocates who believe in the principles of freedom and self-determination.

T-4 Mind Play: Tools for Creativity

John Irvin

"Mind Play: Tools for Creativity" is an interactive workshop that presents creativity as a holistic skill that can be learned and developed. Creativity is more that just a way of thinking. It is inclusive of how we think, act, and speak to one another and ourselves. It is the skill of allowing oneself the freedom to create. This workshop brings to every participant creative techniques and theory that each one can begin to use immediately to be more creative in everyday life.

T-5 Linking General Education Standards , IEP's and Inclusive Classroom Instruction

Cheryl M. Jorgensen

Participants in this TASH Tech will work together in small groups to identify the critical function of general education standards and the essential elements of the curriculum; to write IEP objectives that relate both to the general education curriculum and their priority learning objectives; and to design instructional supports that illustrate how students can be supported in the classroom.

T-6 Developing Augmentative Communication to Support Participation in General Education Classrooms

Michael McSheehan, Rae Sonnenmeier

A thoughtful process is needed to ensure that a stabilized augmentative communication system is not a prerequisite to being included. The phases of developing a system, technology features, and message selection to increase curricular and social participation will be presented through discussion, interactive problem solving, technology exploration, and personal stories.

T-7 Collaborative Teamwork for Inclusive Education: Integrating Therapy and Educational Services

Beverly Rainforth

Legal, philosophical, and research foundations will be established for related services to have more active roles in inclusive education teams. Strategies will be presented for transdisciplinary teamwork, including models of co-teaching and integrated therapy, alternatives to traditional roles and schedules, and frameworks for decision-making. All will be discussed in the context of inclusive education.

T-8 Designing and Implementing Inclusive Curriculum: Teaching Community and Standards

Mara Sapon –Shevin, Mary Fisher, Paula Kluth, Lucille Zeph

This interactive workshop will address strategies for designing and implementing inclusive curriculum for heterogeneous

Continued on page 8

TASH TECH Pre-Conference, Full- Day Workshops

Continued from page 7

learners. Ways of incorporating state standards and IEP objectives within rich, cooperative, multi-level curriculum will be explored and experienced by workshop participants.

T-9 International Inclusion Update

Anne Smith, Roberto Leal, Zuhy Saheed, Diane Richler

An overview and update of some of the activities and vehicles for advocates for inclusion in the international arena will be presented. Background information and status reports about several international inclusion products, activities, networks and organizations will be discussed, including: UN Declaration of Rights of the Child; The Declaration of Managua- How leadership by families of people with disabilities, in cooperation with governments and professionals established an agenda for action; UNESCO Activities in Light of the Salamanca Statement and Framework for Action; The 6th International Congress on Serving Children And Youth in Inclusive Schools; and much, much more. This interactive and exciting day is not to be missed. Come prepared to share your experiences and expertise!!

T-10 Multiple Intelligences in Inclusive Classrooms

Robin Smith, Laurel Garrick Duhaney

This session will emphasize the use of multiple intelligences to enhance academic and social engagement and establish a competence-oriented learning community. Participants will experience music, body sculpture, and kinesthetic games to support academics in inclusive classrooms along with other approaches that support "whole brain" or "brain compatible" learning. Applications at all grade levels will be discussed. Participants are encouraged to bring examples pertinent to students in their school.

T-11 Zen and the Art of Inclusive Recreation Design

Dan Wilkins, Cynthia Burkhour

If work and contribution are the inbreath, then leisure and recreation are the outbreath. One cannot exist without the other in healthy beings or communities. Using this summer 's installation of a Code Plus Play Structure at The Ability Center of Greater Toledo, the co-presenters will discuss the synergy, vision, planning and implementation that goes into providing thoughtful and inclusive opportunities for all members of the community.

T-12 Family Support, Self-Determination and Disability

Susan Yuan, Shelley Dumas, Phil Smith

Sample exercises from Philosophy and Cultural Competence Modules of the nationally offered curriculum: "Family Support, Self-Determination, and Disability." Developed by families, this curriculum considers supports effective if they enable people to build and exercise control over their own lives. Participants will consider such topics as the difference between family-centered and person-centered planning and when each is appropriate; understanding the family as a system; building interdependence and reciprocity; redefining professional roles; analyzing the role that power and control play in building family confidence and competence; and building culturally responsive family support.

An Opportunity for Chapter Leaders to Network and Plan for the Future!

In addition to the TASH Techs that are being held on Wednesday, December 6th, TASH is holding the Annual Chapter Leadership Day – An opportunity for chapter officers and representatives to share ideas, concerns and strategies.

This event has been held on the Wednesday before the conference, in one form or another, for the past five years and has been critical in strengthening relationships between the International TASH Board, Central Office and Chapter Leaders. The day includes opportunities for skill building, informal sharing of ideas and planning for the future. The Chapter Leadership Day has helped new chapters to identify directions for themselves and has assisted established chapters to influence policy and direction within their states. Whether you represent a thriving, a newly established, or a struggling chapter, the 2000 Chapter Leadership Day is an event you won't want to miss!

All current Chapter officers will receive invitations to this exciting day of planning and collaboration. If you are interested in starting a chapter and would like to participate in the 2000 Chapter Leadership Day on December 6th, call Nancy Weiss at 410-828-8274, ext. 101 or e-mail: nweiss@tash.org

Special Pre-Conference Symposium
Co-Sponsored by NADD

HOW TO ADVOCATE FOR EFFECTIVE AND RESPECTFUL MENTAL HEALTH SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES
-OR-
UNDERSTANDING THE PSYCHIATRIC TOWER OF BABBLE

SUE GABRIEL,
PSYCHIATRIC NURSE PRACTITIONER

Most people who support people with developmental disabilities have had little training or experience with the types of psychological/psychiatric problems that the people they support may experience. Though there are important and legitimate uses for psychiatric interventions, including the use of psychotropic medications, often medication is prescribed to restrain a person chemically or simply to reduce behavior problems. The use of medication for chemical restraint has caused many advocates to avoid mental health services for persons with developmental disabilities. As a result, sometimes people's mental health needs go undiagnosed and untreated. This Special Symposium will review a full range of issues in supporting people who have both developmental disabilities and psychiatric diagnoses. These include:

- Understanding and supporting people who are agitated or aggressive. When people have self-injurious behavior, destroy property, or are aggressive towards others, family members and other advocates struggle to understand and reduce the aggression. Often people feel powerless to help. This symposium will provide important information for understanding the stressors that lead to aggression, in all of its various forms, and how family members and staff can support people in positive ways to reduce these behaviors.

- Understanding depression, another major category of psychiatric diagnosis. Participants will gain familiarity with assessment and treatment issues including the appropriate uses of medication and other non-pharmacological options.

- Recognizing the signs of other psychological or psychiatric problems including: bipolar disorder, attention deficit/hyperactivity disorder, anxiety disorders, sleep disturbances, obsessive compulsive disorders, post traumatic stress disorder, schizophrenia and psychotic disorders. Participants will learn to identify when these may be issues for their family member or the people they support and the roles family members, staff and other advocates can play in assuring proper assessment and respectful and effective interventions.

The "Psychiatric Tower of Babble" is a user-friendly, highly participatory symposium designed for those with a heart for advocacy but without a medical degree.

In-Focus Strands

Advocacy

Friday

Strand Coordinator: Mary Hayden

Join this lively strand for a series of presentations on advocacy and self-advocacy. Sessions will be facilitated by advocates and self-advocates and will focus on the skills needed to effect change at both the personal and policy levels. All sessions within this strand will provide opportunities for discussing ideas and for sharing strategies for success.

Developing Effective Supports for Autism at the Systems, Family, and Individual Levels

Friday

Strand Coordinator: Don Kincaid

The four presentations in this strand will address effective strategies and systems change that reflects best practices in autism. These best practice topics include comprehensive positive behavior support, inclusion, natural environments, child and family centered focus, collaborative training and meaningful outcomes.

Older Adults with Developmental Disabilities: Supporting Later Life Choices and Community Options

Thursday

Strand Coordinator: Alan Factor

Older adults with developmental disabilities face the same age-related concern as the general population: filling their increased free time with meaningful activities, coping with the loss of family and friends, and remaining in their own homes as long as possible despite health and functional losses. Yet, older adults have little experience in making choices and in using community resources and supports. The sessions featured in this strand will teach participants how to support older adults in making later life choices and in person-centered planning, and strategies for accessing aging network programs and services and other community supports to meet individual later life choices.

Eugenics, Euthanasia and Assisted Suicide: the History and Resistance

Thursday

Strand Coordinator: Michael Bailey

Eugenics, euthanasia and genocide are part of our history. Not Dead Yet will lead a discussion on that history, the role of the assisted suicide movement, and the recent referendum in the State of Maine.

Community Living

Friday and Saturday

Strand Coordinators: Patti Scott and Joe Wykowski

This strand focuses on a variety of issues concerning living in the community including supports, relationships, employment, and conversion of group living situations to supported living.

Ending the Silence and Invisibility of Crime Victims with Disabilities

Thursday

Strand Coordinator: Lisa Sonneborn

Research shows that people with disabilities are twice as likely to experience a violent crime as are their non-disabled peers. Despite this disturbing trend, crimes against people with disabilities are underreported, and are rarely prosecuted to the full extent of the law. Sessions in this strand will identify barriers to due process, recommend strategies for interagency collaboration, and teach basic personal safety skills.

Early Childhood

Thursday

Strand Coordinator: Alan Berger

This strand includes sessions that highlight critical issues and practices in creating inclusive early education and childcare options for young children with severe disabilities and their families.

Employment

Thursday – Saturday

Strand Coordinator: Michael Callahan

This strand features sessions covering all the hot issues related to the employment of people with disabilities. Topics will include natural supports, choice, conversion, individualized planning and much, much, more!

Family Gatherings

Friday and Saturday

Strand Coordinator: Barbara Buswell

This strand, with its opening crackerbarrel, will frame the current issues facing people with disabilities and their family members. Join other family members as they share strategies, challenges and successes in a variety of topics ranging from childhood to adulthood.

Governmental Affairs

Friday

Strand Coordinator: Mike Auberger

In keeping with the "new millennium" the Governmental Affairs Strand offers a glimpse into the future of advocacy and vital issues facing TASH members and the disability community. In addition, this strand will include the latest information on IDEA and what TASH members need to know and what needs to be done.

Guardianship: Melding TASH Values with Best Practices

Thursday

Strand Coordinator: Dohn Hoyle

This strand includes sessions that discuss guardianship as the last civil rights frontier, exploration of strategies for best practices in alternatives to legal guardianship, and issues related to wills and trusts.

Design and Implementation of Statewide Alternate Assessment System

Friday

Strand Coordinator: Donna Lehr

Included in this strand are sessions in which presenters will describe their states' or districts' models for meeting the IDEA requirement that all students participate in required high stakes accountability system. The emphasis will be on the approaches used to assess students for whom the standard assessment systems are not appropriate.

Inclusive Education: Best Practices

Thursday

Strand Coordinator: Gail McGregor

Join this strand as it highlights sessions

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that offer best practices in creating inclusive education opportunities for people with disabilities.

Postsecondary Choices and Challenges: College as the New Frontier

Friday

Strand Coordinators: Caren Sax and Jeff Strully

Postsecondary education offers new options for people with significant disabilities as they exit high school. Just as tackling the educational environment in elementary and high schools presented new challenges and opportunities, accessing colleges and universities requires creative strategies and collaborative efforts. Join us for a strand that identifies the issues, features effective approaches, and offers real stories from people with disabilities who are attending colleges and universities. We're all still learning, so come share your questions and solutions.

Supporting Students with Severe Disabilities to be Real Members of High School Communities

Thursday

Strand Coordinator: Carol Tashie

Inclusive education is happening across the country. But for many high school students labeled with severe disabilities, their school days involve separate "life skills" classes, community-based instruction, and "transition planning" into sheltered adult environments. This full day strand is designed to offer TASH members the opportunities to hear short presentations from leading experts in the area of inclusive high school and college education, as well as participate in free flowing, round table discussions designed to answer your specific questions and concerns. Join us for a day-long, interactive session, and learn and teach others how high school inclusion can be a reality for all students.

International Inclusion

Thursday

Strand Coordinator: Anne Smith

This strand will explore dimensions of inclusion/exclusion around the world. It will be structured for interactive discussion. Following brief panel presentations, both presenters, and participants will respond to focused discussion questions to identify emerging themes around the global inclusive movements as well as to highlight activities in various nations and regions across several continents.

Inclusion in Urban Schools

Friday

Strand coordinator: Rebecca Salon

This interactive strand highlights what works in urban educational settings — the activities, strategies and approaches through which students with disabilities have been successfully included and educated in their neighborhood schools. Sessions feature approaches to school-wide positive behavioral support, instructional improvements and other school-wide approaches that have resulted in individual and school-wide success.

Whole School Reform and Inclusive Education

Thursday

Strand Coordinator: Michael Peterson

This strand will explore the connection of inclusive education to whole school reform efforts. It includes a series of panel presentations and dialogue with participants. First, a panel will discuss the needs and strategies for building connections with whole school reform efforts based on the experience in schools of the presenters. Second, presenters will share their experiences in engaging in whole school reform in which inclusive education plays a central role. Finally, a panel will discuss the work of the Whole Schooling consortium, and developing whole school reform framework that places inclusive education at the center of the model. Participants are invited to join and contribute to this work.

Recreation Options and Opportunities

Friday

Strand Coordinator: Cindy Burkhour

Recreation improves the quality of our lives and our communities. This strand will present strategies for making recreation inclusion a reality in the lives of children and adults with disabilities.

Literacy

Friday

Strand Coordinators: Leonore Pelligrino-Sino and Amy Staples

Literacy is a critical life skill. The past decade has marked a shift in research, practice and learning. This strand will offer participants the opportunity to become familiar with current research, best practices, support networks, and outcomes related to literacy instruction for all learners.

Serving Culturally and Linguistically Diverse Individuals

Friday

Strand Coordinator: Lynda Baumgardner

Individuals with significant disabilities who come from culturally/linguistically diverse backgrounds may face twice the barriers and segregation. This strand will provide innovative, culturally responsive approaches and examples.

Paraeducator Issues and Practices

Thursday

Strand Coordinator: Michael Giangreco

This strand addresses paraeducator issues and practices ranging from national standards to school and classroom practices.

Personnel Preparation

Thursday – Saturday

Strand Coordinator: Diane Ryndak

Join this strand as it highlights timely issues and progressive strategies for preservice and inservice educators. This strand will also feature sessions regarding post secondary education, as well as a special focus on distance delivery.

Positive Approaches/Positive Behavior Support

Thursday and Friday

Strand Coordinators: Tim Knoster and Rob O'Neill

This strand will highlight practical application and research on positive approaches to supporting individuals with histories of problem behavior. In particular, this strand features ways to expand findings and horizons in research, and translation of research into practice, across home, school and community settings.

Related Services Supporting Inclusive Education

Friday

Strand Coordinator: Beverly Rainforth

Related services including OT, PT, and

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speech/language, can be important supports to inclusive education, but often are provided as separate pull-out services. Sessions in this strand will present principles and strategies to arrange for and provide related services, as IDEA requires, in the least restrictive environment and so they support the education program.

Where Science and Advocacy Meet

Thursday – Saturday

Strand Coordinator: Linda Bambara

TASH is a place where both researchers and advocates can work together to address the needs and concerns of people with disabilities and their families. This strand highlights the emerging synergy between science and advocacy, resulting in the most progressive research in the disability field. Open to all participants, we hope that the research strand sessions will generate excitement about this new generation of research.

Self-Determination

Thursday – Saturday

Strand Coordinator: Elizabeth Obermeyer and Patti Scott

The concepts of self-determination are sweeping the country and indeed the world! The age old principles of choice, authority, respect, freedom and accountability are rising to the forefront at long last. Sessions in this strand will include a cracker-barrel discussion to kick off the strand, followed by sessions on how to reinforce and cultivate the skills needed to practice these elements in youths with disabilities, stories of success and change from parents, people with disabilities, and their circles of support, and recent research findings.

Embracing the Sexuality of Individuals with Significant Disabilities

Thursday

Strand Coordinator: Wanda Blanchett

Sexuality and sexual expression are natural and important aspects of each of our lives. In order for individuals with significant disabilities to express their sexuality in the manner in which they choose, they must have access to complete and accurate information regarding issues of sexuality. This strand will highlight sessions that address issues related to this critical topic.

Spirituality: Honoring the Unique Expressions

Friday

Strand Coordinator: Maureen Keyes

The introduction of spirituality into any conversation yields varied responses from suspicion to relief. This strand contains a variety of perspectives on the topic of spirituality as it relates to community, disability, justice, equity, and leadership.

Students Who Severely Challenge Schools But Who Do Not Have Labels of "Severe" Disabilities

Thursday

Strand Coordinator: Linda Rammler

This strand seeks to apply TASH values and best practices concerning inclusive education, positive behavior supports, family supports, and self-determination to a group of students who have not traditionally been the focus of TASH's advocacy efforts because they do not have labels of severe disabilities.

Professional Development: More Powerful Teaching

Friday

Strand Coordinator: Janice Payne

Professional development is seen as the key to successful school change and restructuring, improved outcomes for all students, and access to inclusive options for individuals with diverse learning styles and disabilities. But what models of professional development are most successful? What are the characteristics of effective professional development? How can we train and retain the best and brightest to teach all of our nation's children and youths? Join this strand, as we learn together.

Innovative Transition Practices for Achieving Typical Adult Life Styles

Thursday – Saturday

Strand Coordinator: Pat Rogan

This strand provides an array of exciting sessions that address positive practices for transition from school to adult life. Session topics include student-centered assessment and planning approaches, innovative options for preparation for adult lives, post-secondary education opportunities, and collaboration with adult services and supports.

The Science and Art of AAC and General Education Curriculum Supports

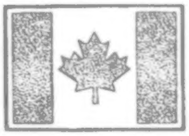
Friday

Strand Coordinators: Michael McSheehan and Rae Sonnenmeir

Use of AAC in general classrooms is increasing. Meaningful experiences for students with disabilities depend on thoughtful curriculum design, technology, and push-in therapies. Join this strand to learn how to increase participation so students using AAC need not reach some arbitrary "proficiency" before being included.

TASH

Conference in Canada??

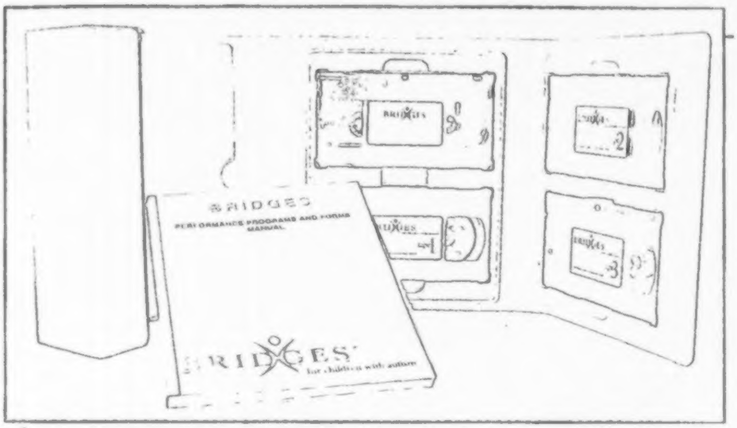


The Conference Committee is looking into the possibility of holding a future year's conference in Canada. The exchange rate is such that hotel and meal costs would probably be reduced by more than one-third. Given that the costs would be lower, does your organization, school or university prohibit travel outside of the United States?

Please respond by telephone (1-800-482-8274, ext. 103) or e-mail <dmarsh@tash.org>.

Thanks for your input!

AUTISM/ASPERGER'S


BRIDGES
PERFORMANCE PROGRAMS AND FORMS MANUAL
BRIDGES for children with autism

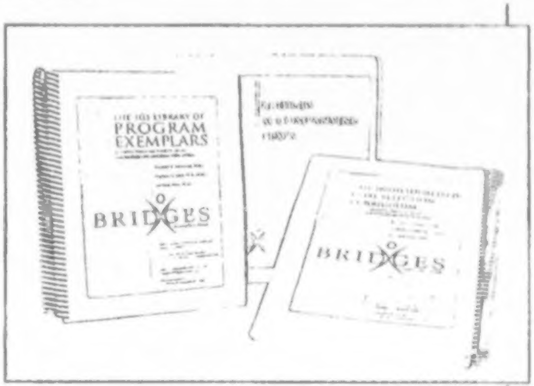
Bridges for Children with Autism

A valuable video series with training manuals for parents and teachers of children with autism

A RICH RESOURCE

Developed by a team of professionals, *Bridges for Children with Autism* is a program to introduce parents and teachers to the **Applied Behavior Analysis (ABA)** approach for helping children with autism. ABA is an intervention based on scientific evidence. The series outlines the Bridges ABA program of systematic instruction that features help in generalization, behavior management, and socialization. Filmed with twelve children diagnosed with autism, pervasive developmental disorder, and Asperger's Syndrome, it details how to create success through reinforcement and sets a positive course for children with autism. Through the use of three videocassettes, the Bridges program addresses the development and review of an appropriate educational plan and can help viewers learn skills in writing targeted programs. By observing children working with professionals in nine content areas, viewers can gain insight into discrete trial and generalization training. The series closes with a tape that features training in data collection, behavior training, and instructional modification. A complete set of instructional manuals complements the video series.

Applied Behavioral Analysis - Treatment of choice for parents & educators



__Tape 1__ – Learn about autism and the application of Applied Behavior Analysis as well as review the development of an appropriate educational plan and how to write targeted programs. (47 minutes)

__Tape 2__ – Observe eighteen different goals across nine content areas, such as attention, self-help, and receptive language, during one-to-one discrete trial instruction and generalization training. (117 minutes)

__Tape 3__ – Learn to properly collect performance and behavior data and observe behavior management techniques, socialization training, and troubleshooting. (79 minutes)

__The Manuals__ – Included with the series are Dr. Raymond Romanczyk's *Individualized Goal Selection Curriculum* and *Library of Program Exemplars*. These are designed to provide the information necessary to implement an ABA program.

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TASH 2000 Sessions By Topic Area

ADVOCACY

Thursday, December 7, 2000

Using the IDEA 1997 Amendments to Create Positive Change in Your District
Time: 11:45 am - 12:45 pm
Speaker: Mark Partin

How to Define Self Advocacy
Time: 3:30 pm - 4:30 pm
Speaker: Gayle Gardner

Surrogate Parents: Protecting the Educational Rights of Children and Youth Under State Guardianship
Time: 3:30 pm - 4:30 pm
Speakers: Lucille Zeph, Charles Zeph

Friday, December 8, 2000

Attitudes and Advocacy: Practicing What We Preach
Time: 8:00 am - 9:00 am
Speakers: Donna Gilles, Winnie Roberson Gayler, Tia Nelis, Elizabeth Obermayer

Taking Control of Personal Planning: A Training Project by and for Self Advocates
Time: 9:15 am - 10:15 am
Speakers: Laurie Kimball, Tracy Hancock, Emma Haferman

"Mixed Voices" A Training Curriculum on Inclusion for Board Participation
Time: 12:15 pm - 2:30 pm
Speaker: Sharon King

Discipline Under IDEA's New Federal Regulations
Time: 2:45 pm - 3:45 pm
Speakers: Selene Almazan, Debra Feldman

How to Achieve Inclusion Under IDEA: A Step by Step Process
Time: 4:00 pm - 5:00 pm
Speakers: Patricia Cox Waldman, Judith Terle

Saturday, December 9, 2000

"Planning for the Future of your Special Needs Child"
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Nadine Vogel

TAKE CONTROL! Be Your Own Advocate - Techniques for Cutting Through Red Tape!
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Jenny Wright, Heather Morrison

ADA Compliance in Medical Facilities: "What if You Couldn't Visit Your Own Doctor?"
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Jennifer Ross Schlussler

Rights, Safety, and Privacy
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Kenny Miller

Mark, Set, Go.....Leadership for All
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Diana Robishaw

A Self-Advocacy Training Team....Supporting One in Your Community
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Cherie Tessier

Speaking for Ourselves
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Glennis Gold

Developing Advocacy Networks for a Stronger Voice
Time: 10:00 am - 11:00 am
Speakers: Vendella Collins, Claudia Combs Wise

Advocacy-in-Action: Increasing Access & Opportunities Through Partnerships
Time: 11:15 am - 1:30 pm
Speakers: Rebecca S. Salon, Ricardo Thornton, Robert Kennedy, Germaine Payne

AGING

Thursday, December 7, 2000

P.C.P- Enhancing the Lives of Aging Individuals with Developmental Disabilities
Time: 2:15 pm - 3:15 pm
Speakers: Linda McDowell, Edwin Butler

Planning and Promoting Positive Aging Experiences for Individuals with Developmental Disabilities
Time: 3:30 pm - 4:30 pm
Speaker: Margaret Nygren

ASSISTIVE TECHNOLOGY

Thursday, December 7, 2000

The Inclusion of Students Labeled with Severe/ Profound Disabilities in Regular Classroom Subject Areas
Time: 10:30 am - 11:30 am
Speaker: Peggy Locke

Assessing Children's Assistive Technology Needs through Video Conferencing
Time: 4:45 pm - 5:45 pm
Speakers: Thomas J. Simmons, Preston Lewis, Debra Bauder

Saturday, December 9, 2000

Simple Technology Ideas from Around the Globe
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Peggy Locke

Assistive Technology Made Simple
Time: 10:00 am - 11:00 am
Speakers: Sara Brannan, Katrina Dennison

AUTISM

Friday, December 8, 2000

The Extinction of the Dinosaur and the Evolution of an Agency Wide PBS Delivery Model for Children with Autism
Time: 12:15 pm - 1:15 pm
Speakers: Jennifer McFarland, Barbara Becker-Cottrill

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Using Positive Behavior Support as the Framework of Early Intervention for Young Children with Autism
Time: 1:30 pm - 2:30 pm
Speakers: Lise Fox, Pamelazita J. Buschbacher, Ann E. Dillon

Contemporary Approaches in Applied Behavior Analysis: Child Centered Applications in Natural Environments
Time: 2:45 pm - 3:45 pm
Speaker: Cindy L'Abbe

Strategies for Developing and Implementing Learning Priorities for Individuals with Autism
Time: 4:00 pm - 5:00 pm
Speakers: Marjorie Russell, Nila Benito

COLLEGE

Friday, December 8, 2000

College: Wishful Thinking or The Next Logical Step?
Time: 12:15 pm - 1:15 pm
Speakers: Caren Sax, Jeffrey L. Strully

Partnering with Universities
Time: 1:30 pm - 2:30 pm
Speakers: Cate Weir, Carol Tashie

Lessons Learned from the National Center for the Study of Postsecondary Educational Supports
Time: 2:45 pm - 3:45 pm
Speakers: Robert A. Stodden

What Families are Asking About Postsecondary Education
Time: 4:00 pm - 5:00 pm
Speaker: Elisabeth Healey

COMMUNICATION

Thursday, December 7, 2000

The Conversational Approach in a Person-Centered Program
Time: 11:45 am - 12:45 pm
Speaker: Julie Tuifel

Increasing Appropriate and Effective Communication Exchanges Between Typical Peers and Students Labeled with Severe Disabilities
Time: 2:15 pm - 3:15 pm
Speaker: Kathleen Stremel

Friday, December 8, 2000

Bringing the World of Voice to Individuals Labeled with Severe Disabilities
Time: 8:00 am - 9:00 am
Speakers: Patricia Wright

The Lonesome Doves Ride Again!
Time: 9:15 am - 10:15 am
Speakers: Rosa McAllister, Melanie Ketchem, Will Turnbull, Renee Chastain, Chammi Rajapatirana, David Fialkowski, Tom Wink, Jennifer Paige Seybert

Learning to Speak in Middle School: Supporting the Development of Speed Through Typing
Time: 12:15 pm - 1:15 pm
Speakers: Jamie Burke, Sheree Burke, Christi Kasa-Hendrickson, Alicia Broderick

Saturday, December 9, 2000

Practical Ways to Assess and Teach Pre-Language Communication Skills
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Kathy Gilman

Listening to Individuals Who Do Not Use Words to Communicate
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Vicki Gerrits

Continued on page 17

Free!

What's free and how can you take advantage of it? Why, registration for volunteers to this year's information-packed, exciting TASH Annual Conference in beautiful Miami Beach, Florida, of course!

If you would like to attend the conference and save on registration fees, this is the deal for you! As a volunteer, you donate a minimum of 10 hours of service during the conference in exchange for complimentary registration to attend any of the more than 350 sessions, workshops and discussion groups on topics ranging from Advocacy to Urban Education Issues and everything in between during your non-volunteer periods.

Whether you've participated as a volunteer before, or would like to do so for the first time, your services are urgently needed as a Conference Volunteer!

If you are interested in receiving more information or a volunteer application, please contact Priscilla Newton, Volunteer Coordinator, at 1-800-482-8274, ext. 102 or send an e-mail to <pnewton@tash.org>

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Funds Available for Families to Attend the TASH Conference!

Through the generosity of the Jacobs Family, TASH is pleased to continue the Emma Rose Scholarship Fund. The purpose of the scholarship fund is to foster the growth of parent advocacy and activism by honoring two parents each year who have made a difference in the lives of people with disabilities.

We are accepting nominations (self-nominations are encouraged!) for this year's scholarship. Scholarship recipients will have their conference registration fee waived and their travel and hotel expenses will be covered. Scholarship recipients will be invited to present at the TASH conference. Recipients are asked to commit to raising $200 annually for the next two years toward the continuation of the scholarship fund. This year's scholarship recipients should be willing to participate in selecting next year's recipients.

To apply, send a letter describing why you or the person you are nominating should be selected for this honor. Letters should be received by October 15th. Send to: Nancy Weiss, TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. Letters also can be sent by e-mail (nweiss@tash.org) or fax: 410-828-6706. For questions, call Nancy at 410-828-8274, ext. 101

Donations for the Emma Rose Scholarship are being accepted and can be made to TASH at the address above.

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The FC Coalition of Indiana-Serving Facilitated Communication Users and Facilitators in the Home, School, and Community
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Winifeld Wetherbee, Nancy Kalina, Kim Davis, Ian Wetherbee

A "Textbook" Case of Reproduction: Representations and Ideologies in Introductory Special Education Textbooks
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Nancy E. Rice

Literacy and Down Syndrome
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: John Elkins

COMMUNICATION SUPPORT & CURRICULUM DESIGN

Friday, December 8, 2000

Please note: The following sessions take place within a strand and the chairpersons are still in the process of identifying speakers, to be announced at a later date.

Considering AAC
Time: 12:15 pm - 1:15 pm

General Education and AAC: How Perfect! How to Perfect?
Time: 1:30 pm - 2:30 pm

AAC, Assessment, and Cognitive Labels
Time: 2:45 pm - 3:45 pm

Synthesis and Reality: Stories of Success and Struggle
Time: 4:00 pm - 5:00 pm

COMMUNITY LIVING

Thursday, December 7, 2000

Life in the City: Issues Related to Residential Supports and Social Networks in Urban Areas
Time: 10:30 am - 12:45 pm
Speaker: Pam Walker, Nancy Rosenau

Overcoming Challenges to Achieve Success! Anthony's Story
Time: 2:15 pm - 4:30 pm
Speakers: Connie Ellington, Patti Scott, Reggie Regrut, Anthony Emili

Enhancing Community Living of Minority Persons with Disabilities
Time: 4:45 pm - 5:45 pm
Speaker: Ming-Gon John Lian

Friday, December 8, 2000

People with Disabilities Get Involved in Neighborhood Life
Time: 8:00 am - 10:15 am
Speaker: Carolyn Carlson

Creating and Sustaining Co-operative Partnerships Between Staff and Family and Friends
Time: 12:15 pm - 1:15 pm
Speaker: Susannah Joyce

A Day in the Life of a Community Builder: Connecting People to Their Neighbors and Neighborhoods
Time: 1:30 pm - 2:30 pm
Speakers: Fredda Rosen, Emily Ellis, Ralph Sanchez, Steven Hernandez

Communities of Tommorow: Think Tank on Community and Economic Equity
Time: 2:45 pm - 5:00 pm
Speakers: Joe H. Wykowski, Jay F. Klein, Patti Scott, Judith Snow

Saturday, December 9, 2000

TILL's Creative Living Options - Partnership in Developing Life Shares
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Dafna Krouk-Gordon, Denise Aronson, Dana Appleford

It's Not Just About What You Do, It's What You Stop Doing (Abandoning the Continuum)
Time: 10:00 am - 12:15 pm
Speakers: James Meehan, Gail Fanjoy

CREATIVE AND PERFORMING ARTS

Thursday, December 7, 2000

How Big is Your Circle?
Time: 3:30 pm - 5:45 pm
Speaker: Jeff Moyer

Friday, December 8, 2000

Utilizing Arts Activities to Teach Disability Awareness
Time: 9:15 am - 10:15 am
Speakers: Heather Downey, Gay Drennon, Marion Winters

Saturday, December 9, 2000

Using Art as a Medium for Impacting Communication, Behavior and Literacy with Students identified with Autism
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Annie Hawkins, Irena Woodham

CRIMINAL JUSTICE

Thursday, December 7, 2000

Criminal Victimization and People with Disabilities
Time: 2:15 pm - 3:45 pm
Speakers: Lisa Sonneborn, Rosemary Willingham, Audrey Badger, Wendi Demchick-Alloy, Beverly Frantz, James McAfee, Terri Pease

Personal Safety for People with Disabilities
Time: 4:00 pm - 5:30 pm
Speaker: Libby Harman

Listening Room
Time: 5:30 pm - 8:00 pm
Speaker: Lisa Sonneborn

Saturday, December 9, 2000

Ending the Silence and Invisibility of Crime Victims with Disabilities
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Lisa Sonneborn, Beverly Frantz

Continued on page 18

Continued from page 17

DISTANCE EDUCATION

Friday, December 8, 2000

LIVE!: Experiencing Interactive Courses in Severe Disabilities Over the Internet

Time: 8:00 am - 10:15 am
Speaker: Richard Kiefer-O'Donnell, Fred Spooner, Martin Agran

EARLY CHILDHOOD

Thursday, December 7, 2000

Early Childhood Crackerbarrel

Time: 10:30 am - 11:30 am
Speaker: Alan Berger

Creating Inclusive Early Care Communities: Building a Foundation for Cooperative Behavior

Time: 11:45 am - 12:45 pm
Speakers: Linda Labas, Martie Kendrick

Saturday, December 9, 2000

Play and Learn - Preschool Curriculum

Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Patricia Wright

Promoting Continuity and Inclusion for All Young Children and Their Families

Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Wayne L. Fox

The Effects of Journal Writing on Stress Levels of Parents after the NICU

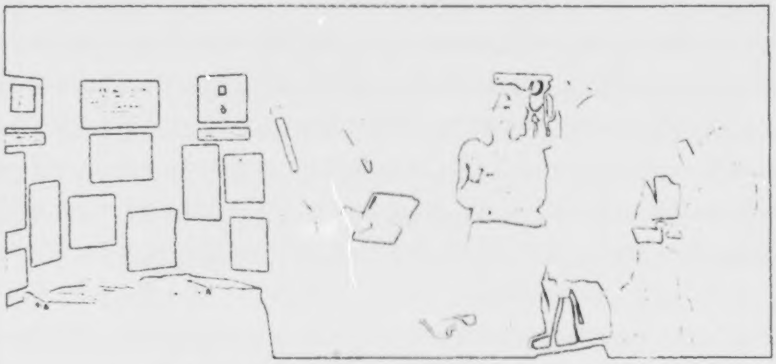
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Leasha Barry

EMPLOYMENT AND CAREERS

Thursday, December 7, 2000

Employment Trends for the Year 2000: Challenges and Opportunities

Time: 10:30 am - 11:20 am
Speaker: John Butterworth



*On Saturday morning enjoy a continental breakfast while visiting an impressive array of poster presentations set up in the exhibit hall. This is a great opportunity to speak one-on-one with presenters from around the world who have prepared an interactive presentation on a variety of topic areas. Feel free to take your time to visit with each poster presentation, as **there will be no breakout sessions scheduled during this exclusive exhibit and poster presentation time.** If you are interested in presenting a poster session, please contact Kelly Nelson at knelson@tash.org or by phone at 410-828-8274 ext. 105 to receive an application.*

One-Stop Centers: Employment Services in a Fully Inclusive Setting

Time: 11:25 am - 12:15 pm
Speaker: David Hoff

Expanding Self Directed Supports

Time: 12:20 pm - 1:00 pm
Speaker: Marilyn Bown, Rick Cobia, Aaron Hillman

Job Development for the People Labeled with Severe Disabilities: A Process That Works

Time: 2:15 pm - 3:15 pm
Speakers: Melinda Mast, Joan Sweeney, Joe Skiba

Looking For a Job? Strategies for Locating, Obtaining, and Maintaining Work in Rural Areas

Time: 3:30 pm - 4:30 pm
Speakers: Jeffrey Hooke, Lee Hockridge

Corporate Job Development: In Search of White Collar Jobs

Time: 4:45 pm - 5:45 pm
Speaker: Hans Swemle

Friday, December 8, 2000

Production of Income through Micro-Enterprises

Time: 8:00 am - 9:00 am
Speakers: Doreen Rosimos, Darcy Smith, Jay Gleason, Sheldon McLean

Self-Employment for Transition-Age Students

Time: 9:15 am - 10:15 am
Speakers: Michael Callahan, Teresa Callahan, Norciva Shumpert

How I Contribute: See What I'm Saying

Time: 12:15 pm - 1:10 pm
Speakers: Shelley Dumas, Veretta Anderson, Carolyn Robinson, Katherine Dumas

Beyond Food, Filth, Flowers, Folding and Fetching: It's All About Opportunity

Time: 1:15 pm - 2:10 pm
Speakers: Deborah A. Gilmer, Alan Kurtz, Kathy Son, Lenny Berry

Discovering Employment with Students, Families, and Teachers

Time: 2:15 pm - 3:15 pm
Speakers: Norciva Shumpert, Twinkle Morgan

The Effects of Career Choice on Employment Outcomes

Time: 3:15 pm - 4:15 pm
Speakers: Lori Garcia, Bruce M. Menchetti

Ecological versus Standardized Vocational Assessments

Time: 4:15 pm - 5:00 pm
Speakers: Edward Grasso, Caroline Dipipi

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Continued from page 18

Saturday, December 9, 2000

From Concept to Reality: Community Options Conversion Project
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Dave Vasa

Critical Factors in the Employment of Persons Labeled with Severe Disabilities Who Use Assistive Technology
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Fran Pollock Prezant

Who is Working Where? A National Estimate of Job Placements for Adults Labeled with Mental Retardation
Time: 10:00 am - 11:00 am (Poster Session)
Speaker: Marjorie Olney

Project RSVP: Expanding Opportunities for Vocational Rehabilitation
Time: 11:15 am - 12:15 pm
Speaker: Jane Rath

Supported Employment is What You Say It Is!
Time: 12:30 pm - 1:30 pm
Speakers: Shelley Wells, Carolyn Robinson, Veretta Anderson

EUTHANASIA RESISTANCE

Thursday, December 7, 2000

Eugenics, Euthanasia and Assisted Suicide: The History and Resistance
Time: 10:30 am - 12:45 pm
Speakers: Michael Bailey, Marsha Katz, Bob Liston, Michael Reynolds

FAMILY

Thursday, December 7, 2000

Nurturing with Daddy Ron and Son Micah
Time: 2:15 pm - 3:15 pm
Speakers: Ron Taylor, Micah Taylor

Friday, December 8, 2000

Crackerbarrel on Family Issues
Time: 12:15 pm - 1:15 pm
Speaker: Barbara Buswell

Partnering with Families to Support Teacher Education
Time: 1:30 pm - 2:30 pm
Speakers: William Sharpton, Rose A. Gilbert, Margaret Lang

Sibshop: A Prevention Model for Sisters and Brothers
Time: 2:45 pm - 3:45 pm
Speakers: Pearl Wollin, Joan Carter

Recognizing Autism in Infancy
Time: 4:00 pm - 5:00 pm
Speaker: Janet Duncan

Saturday, December 9, 2000

Life Planning for Persons with Special Needs
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Kevin Perline

Experience the Power of Assistive Technology at Home
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Mary Kay Walch

WEBCATT: We Build Communication Access Through Technology
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Sandra Alper, Charlotte Mull, Steve Noyes

Grandparents and the Young Child
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Sylvia Martin

Technical Assistance: A Parent's Perspective
Time: 11:00 am - 12:15 pm
Speakers: Laura L. Triulzi, Melinda Morrison, Maurice Escobar, Linda Parras

Emotions and Coping
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Georgia Pappas

Eugene Marcus and His War Against Autism: A Dad/Son Co-Memoir
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: David Marcus, Eugene Marcus

When School Isn't Enough
Time: 10:00 am - 11:00 am
Speakers: Beverly Fields, Stephanie Mahfood

A Foot in Both Camps: Parents Who Are Also Professionals
Time: 11:15 am - 12:15 pm
Speakers: Deanna Horstmeier, Ann Turnbull, Bud Fredericks

Beyond the Basics, to the Belief
Time: 12:30 pm - 1:30 pm
Speakers: Julie Pater, Margaret Cantey, Nancy Howe, Nancy Moore

GOVERNMENTAL AFFAIRS

Friday, December 8, 2000

MiCASSA and What It Means To You
Time: 12:15 pm - 1:15 pm
Speaker: Michael Auberger

The Olmstead Decision Made Easy
Time: 1:30 pm - 2:30 pm
Speaker: Robert Kafka

ADAPT: Why Don't You Belong?
Time: 2:45 pm - 3:45 pm
Speaker: Linda Anthony

GUARDIANSHIP ALTERNATIVES

Thursday, December 7, 2000

Alternatives to Guardianship
Time: 2:15 pm - 3:15 pm
Speakers: Dohn Hoyle, Kathleen Harris

Creative Solutions as Alternatives to Guardianship for Adults with Disabilities
Time: 3:30 pm - 4:30 pm
Speakers: Freya Koger, Linda Bambara

Estate Planning: An Alternative to Guardianship
Time: 4:45 pm - 5:45 pm
Speakers: Kathleen Harris, Dohn Hoyle

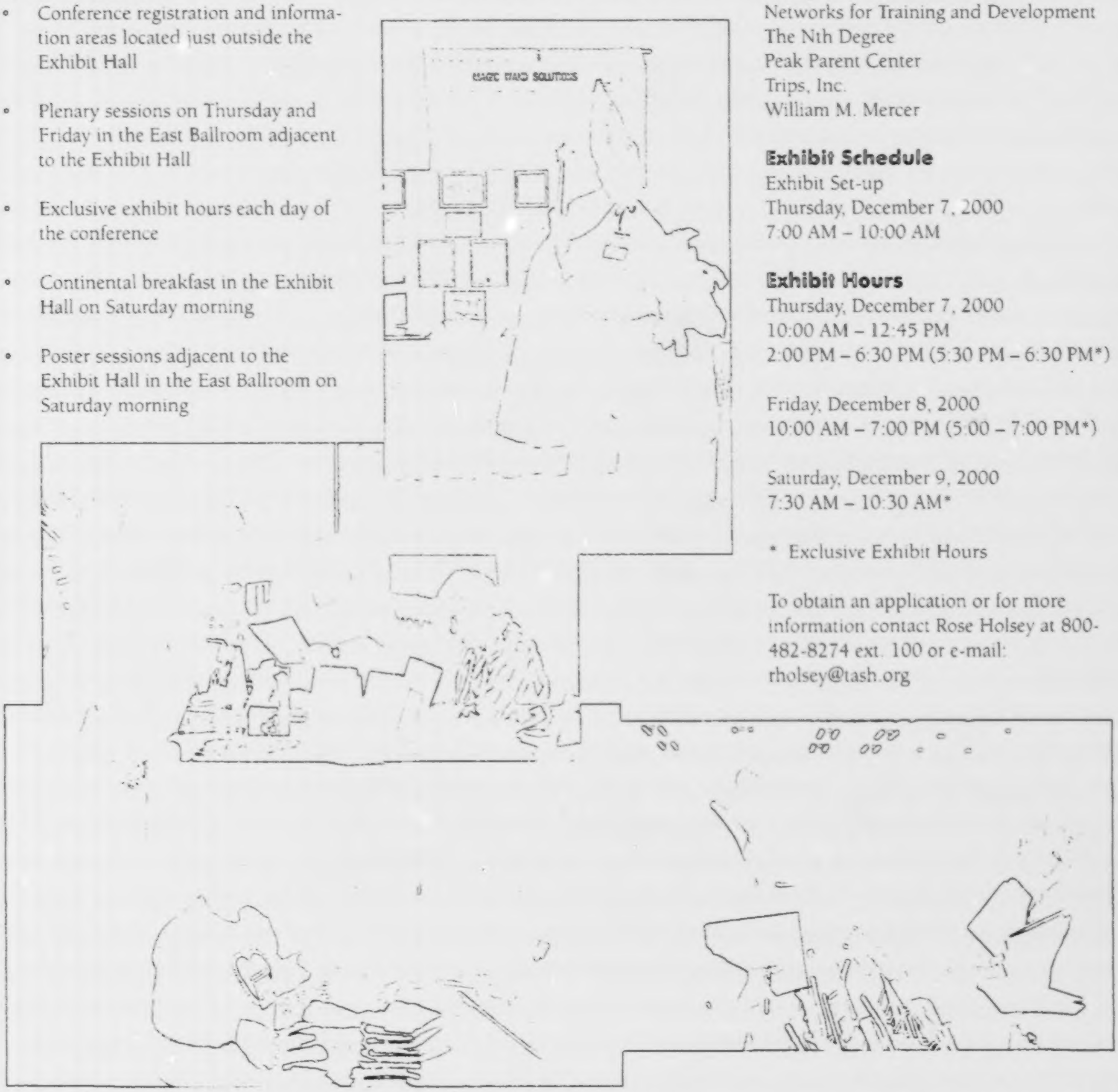
Continued on page 21

2000 TASH Conference Exhibits

Join us in Miami Beach for what is sure to be one of TASH's most informative and festive annual meetings ever! Not only will this year's conference highlight exciting new presentations and returning favorites, but this year marks TASH's 25th anniversary, as well. The Exhibit Hall will be the hub for our Silver Anniversary celebratory events, including the site of TASH's very first Silent Auction!

Daily events to increase booth traffic include:

- Conference registration and information areas located just outside the Exhibit Hall
- Plenary sessions on Thursday and Friday in the East Ballroom adjacent to the Exhibit Hall
- Exclusive exhibit hours each day of the conference
- Continental breakfast in the Exhibit Hall on Saturday morning
- Poster sessions adjacent to the Exhibit Hall in the East Ballroom on Saturday morning



Some of the many exhibitors to be seen at the 2000 TASH conference include:

AbleNet
APSE
Aurora Ministries
Brookes Publishing Company
Center for Technical Assistance
Human Policy Press, Center on Human Policy
Diverse City Press
Inclusion Press International
International Rett Syndrome Association
Lifestyle Enhancement Services
Networks for Training and Development
The Nth Degree
Peak Parent Center
Trips, Inc.
William M. Mercer

Exhibit Schedule

Exhibit Set-up
Thursday, December 7, 2000
7:00 AM – 10:00 AM

Exhibit Hours

Thursday, December 7, 2000
10:00 AM – 12:45 PM
2:00 PM – 6:30 PM (5:30 PM – 6:30 PM*)

Friday, December 8, 2000
10:00 AM – 7:00 PM (5:00 – 7:00 PM*)

Saturday, December 9, 2000
7:30 AM – 10:30 AM*

* Exclusive Exhibit Hours

To obtain an application or for more information contact Rose Holsey at 800-482-8274 ext. 100 or e-mail: rholsey@tash.org

Continued from page 19

HIGHER EDUCATION

Thursday, December 7, 2000

Creating Community and a New Train for Non-Categorical Certification: Re-Imagining Teacher Training in Special and General Education

Time: 3:30 pm - 4:30 pm
Speakers: Patrick Schwarz, Valerie Owen, Pennie Olson

Friday, December 8, 2000

Strategies for Teaching About Persons Labeled with Severe Disabilities

Time: 12:15 pm - 2:30 pm
Speakers: Keith Storey, Diane Baumgart, Diane Browder, Janis Chadsey, June Downing, Carolyn Hughes, Donna Lehr, Beverly Rainforth

Elements of Postsecondary Programs for Students Labeled with Severe Disabilities Ages 18-21 in Maryland

Time: 2:45 pm - 3:45 pm
Speakers: Meg Grigal, Sherril M. Moon, Debra Neubert

Students With Disabilities as Agents of Change: Transitioning into Leadership

Time: 4:00 pm - 5:00 pm
Speakers: Debbie Webster, Nancy Reid

Saturday, December 9, 2000

Seen But Not Heard: The Representation of Disability in Professional Training Textbooks

Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Nancy Rosenau

Disability Related Service Needs and Satisfaction of University Students

Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Alo Dutta, Chrisann Schiro-Geist

INCLUSIVE EDUCATION

Thursday, December 7, 2000

The Principal and the Parent — Collaboration for the Sake of Kids

Time: 10:30 am - 11:30 am
Speakers: Colleen Horton, Bill Henderson

Strategies to Facilitate Whole School Reform

Time: 10:30 am - 12:45 pm
Speakers: Ann T. Halvorsen, Mary Falvey, Deborah L. Tweit-Hull, Dona Meinders, Jacki L. Anderson, Linda Lee, Nancy Franklin

Competence Oriented Teaching: Awareness and Practice

Time: 11:45 am - 12:45 pm
Speaker: Robin Smith

Creating Collaborative Instructional Teams: An Organizational Perspective

Time: 2:15 pm - 3:15 pm
Speakers: Gail Ghere, Jennifer York-Barr, Julie Mahoney

Friday, December 8, 2000

Giving Up the Edge

Time: 9:15 am - 10:15 am
Speakers: Karen Topper, Dawn Arsenault, Carol Warner, Tracy Thresher

Saturday, December 9, 2000

Grade to Grade Transition Strategies for "Teams" Supporting Students with Autism

Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Nila Benito, Marjorie Russell, Linda Montgomery

Whole Schooling: What Have We Learned About Successful Inclusion and Authentic Curriculum in Wisconsin's Poor Rural and Urban Schools?

Time: 10:00 am - 11:00 am
Speakers: Kim S. Beloin, Paula Dehart, Sandi Gallagher, Valerie Hopkins

"Not One More Thing" A Longitudinal Study Examining The Process Of Implementing Positive Behavior Supports Within An Urban Middle School

Time: 10:00 am - 11:00 am
Speaker: Hank Edmonson

Using a Building-Level Planning Process to Promote Inclusion

Time: 10:00 am - 11:00 am
Speakers: John J. McDonnell, Connie Mathot-Buckner, Nadine Thorson, Cathi Allen, Jeri Mendel

A Follow-up Study of Inclusion Practices in Pennsylvania Secondary Schools

Time: 10:00 am - 11:00 am
Speakers: Steven R. Lyon, Becky Knickelbein

Case Studies in Inclusive Leadership

Time: 10:00 am - 11:00 am
Speakers: Diane Ketelle, Kathleen Gee

Continued on page 23

NOT ABLE TO EXHIBIT THIS YEAR?

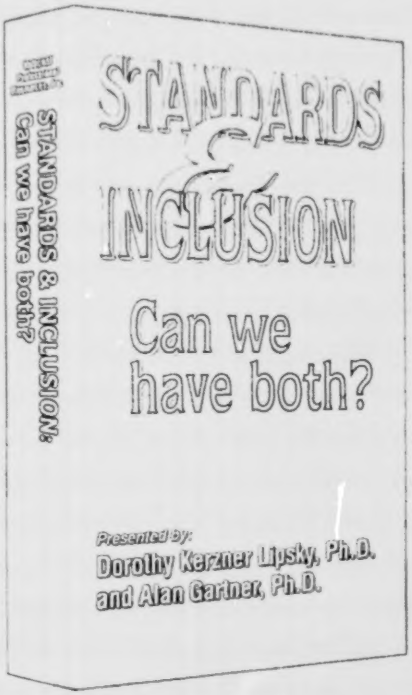
You can still reach the TASH Audience!

If you are unable to have a booth in the TASH exhibit hall this year, but would like to take advantage of the opportunity to have your books, videos, brochures, catalogs, or pamphlets distributed or displayed to TASH Conference attendees, then this offer is for you!

Brochures announcing new publications, videotapes, conferences and workshops, or books which are targeted to parents, advocates, professionals, educators, community service providers, or anyone attending the conference are welcome. For $119.00 we will display your product in the exhibit show!

If you would like an application to be part of the Display Table, please contact Kelly Nelson at 1-800-482-8274 x105 or knelson@tash.org.

Standards & Inclusion: Can we have both?



DOROTHY KERZNER LIPSKY, PH.D. AND ALAN GARTNER, PH.D.

The move toward higher standards in our nation's schools has raised a major dilemma for educators committed to the inclusion of students with disabilities. How can these students truly succeed in a learning environment where academic standards and formalized testing are increasing?

Dorothy Kerzner Lipsky and Alan Gartner, from the National Center on Educational Restructuring and Inclusion at the City University of New York, address many of the critical issues facing educators who are supporting students with disabilities in inclusive settings.

Through a dynamic and powerful presentation Drs. Lipsky and Gartner discuss: The Consequences of Higher Standards, The Seven Factors of Successful Inclusion, The Reauthorization of I.D.E.A., The Restructuring of Our Schools.

Authors: Manuscripts Wanted. For guidelines, see www.nprinc.com

Visit schools across the country and observe first-hand how the learning needs of all students are being successfully met in general education environments. Learn how special education is a service not a location. Understand that the inclusion of students is not determined solely by where they are placed, but by their full and complete access to the same curriculum as the general education population.

Whether a regular or special educator, this video is a must for pre-service and inservice training.

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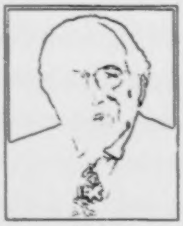
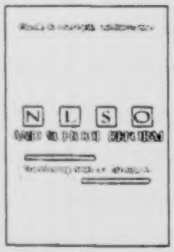
DOROTHY KERZNER LIPSKY


ALAN GARTNER

ABOUT THE AUTHORS:

Dorothy Kerzner Lipsky is Director of the National Center on Educational Restructuring and Inclusion, and Alan Gartner is Dean for Research. Both are at The Graduate School and University Center, The City University of New York.



COMPANION BOOK:

Inclusion and School Reform: Transforming America's Classrooms

DOROTHY KERZNER LIPSKY, PH.D. AND ALAN GARTNER, PH.D.

Emphasizing the need for the concurrent development of inclusion and school restructuring, this book gives policy makers, administrators, school board members, teachers, and parents a solid understanding of the process of school reform, as well as a vision for the 21st century.

1997, soft cover, 414 pages Order #INSR-TASH1 $36.95

Order from: *National Professional Resources, Inc.*, 25 South Regent St., Port Chester, NY 10573 Phone: 1-800-453-7461; Fax: 914-937-9327; *World Wide Web Site: www.nprinc.com.* Amex, Visa, MasterCard, prepaid and purchase orders accepted. Shipping & handling: Add $4.50 per book; $5 per video. For book orders of $50 and above, add 10% — not to exceed $40. Canada add 20% to all orders. Federal Tax ID #132619258. Free catalogs available upon request.

Authors Wanted: For manuscript submission guidelines, call Acquisition Editor: 1-800-453-7461.

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Collaborative School Reform: Restructuring For All Students
Time: 11:15 am - 12:15 pm
Speakers: Nancy Caldwell-Korpela, Margaret Keeler, Joy Larson, Jack Jorgensen

Inclusive Education as "Outcome"? Intensive Behavioral Intervention for Young Children Labeled with Autism
Time: 11:15 am - 12:15 pm
Speakers: Alicia Broderick

INCLUSIVE EDUCATION-ASSESSMENT

Thursday, December 7, 2000

Building Linkages between Assessment and Instruction: Outcomes-Oriented Curricula Design for Students with Multiple Disabilities
Time: 2:15 pm - 3:15 pm
Speaker: Jan Writer

Inclusive Education Strategies: Linking Program Development to Assessment
Time: 4:45 pm - 5:45 pm
Speakers: Pamela W. Holmdal, Joan Pabisz-Ruberton

Friday, December 8, 2000

Standards Based Reform and Assessment
Time: 8:00 am - 9:00 am
Speaker: Douglas Fisher

Implementing a Portfolio-Based Alternate Assessment System: Issues, Insights and Recommendations
Time: 9:15 am - 10:15 am
Speakers: Kellie Anderson, Mary Ann Mieczkowski, Brian Touchette, Shaunna Crossen, Donald L. Peters

Including Students Who Are Deafblind in Statewide Assessments
Time: 12:15 pm - 1:15 pm
Speakers: Jacqueline Farmer Kearns, Maria White, Leah Horvath, Stephanie Kampfer, Mary Calie, Joyce Russo

Alternate Assessment in North Carolina
Time: 1:30 pm - 2:30 pm
Speakers: Diane Browder, Fred Spooner, Kathy Fallin, Naia Ward

A Pilot Study of the Pennsylvania Alternate System of Assessment
Time: 2:45 pm - 3:45 pm
Speakers: Naomi Zigmond, Steven R. Lyon, Donna Lehr, Audrey Kappel

Alternate Assessment Portfolios: Which Items Should be Included? How Will These Measures Make a Difference?
Time: 4:00 pm - 5:00 pm
Speaker: Alison Ford

Saturday, December 9, 2000

Developing Communication within Curriculum: The REAL Prerequisite to Cognitive Assessments
Time: 10:00 am - 11:00 am
Speakers: Rae Sonnenmeier, Michael McSheehan

INCLUSIVE EDUCATION: BEST PRACTICE

Thursday, December 7, 2000

Lee's Determination to be Included in Grades 4-12
Time: 10:30 am - 11:30 am
Speakers: Barbara Ayres, Deborah L. Hedeen

Planning for the Diverse Classroom
Time: 11:45 am - 12:45 pm
Speakers: Linda Davern, Roberta F. Schnorr, James Black

Identifying Learning Opportunities in General Education Classrooms: Applied Creativity
Time: 2:15 pm - 3:15 pm
Speakers: Joanne Eichinger, June Downing

Systematic Instruction within the General Education Curriculum
Time: 3:30 pm - 4:30 pm
Speakers: Kathleen Gee, Barbara Thompson, Diane Lipton

Everybody Here Can Play: Promoting Inclusive Behavior in Classrooms
Time: 4:45 pm - 5:45 pm
Speaker: Mara Sapon-Shevin

Friday, December 8, 2000

Using Daily Schedules to Teach Academic Skills to Students Labeled with Moderate to Severe Disabilities
Time: 8:00 am - 9:00 am
Speakers: June Downing, Kathryn D. Peckham-Hardin

Safe and Supportive Inclusive Classrooms
Time: 9:15 am - 10:15 am
Speakers: Wayne L. Fox, Tim Fox, Kelly Roche, Wes Williams

Saturday, December 9, 2000

Centering on Children: Learning from Abroad
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Cynthia F. Sutton

Inclusive Assessment: One State's Approach to Making All Mean All
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Martha Toomey, Mary Ann Mieczkowski

Strategies to Enhance the School and Family Lives of Individuals with Deaf-Blindness
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Kathryn Haring, David Lovett, Jan Watts, Lisa Lawter

Strategies for Collaborating to Differentiate Instruction
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Nicki McGowan, Jessica Beasley, Melissa A. Brown

An Inclusive Partnership
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Vicki A. McGinley, Donna Wandry, George Drake

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Providing Continuity in Special Education Inclusion Services: Preschool to School Age
Time: 10:00 am - 11:00 am
Speakers: Linda E. Rosenthal, Janice Payne

Small Class Size: The Key to Successful Inclusion
Time: 10:00 am - 12:15 pm
Speakers: Julie Caustan-Theoharis, George Theoharis

INCLUSIVE EDUCATION: INTERNATIONAL INCLUSION

Thursday, December 7, 2000

Meeting Individual Needs in the Inclusive Classroom: A Case Study from Norway
Time: To be determined
Speakers: Inger Elisabeth Eigeland, Michael D. Arthur

Global Partnerships
Time: To be determined
Speakers: Mary E. McNeil, Maria Bove

Inclusion in Italy: It's Simply Education
Time: To be determined
Speaker: Carol Berrigan

INCLUSIVE EDUCATION: HIGH SCHOOL

Thursday, December 7, 2000

Why Are We Still Asking Why?
Time: 10:30 am - 11:30 am
Speaker: Jeffrey L. Strully

Asking the Essential Questions About High School Curriculum
Time: 11:45 am - 12:45 pm
Speaker: Cheryl M. Jorgensen

Why Not Community Based Instruction?
Time: 2:15 pm - 3:15 pm
Speaker: Mary Schuh

If Everyone Agrees Friendships Are Important, Why Do So Many Kids Still Not Have Real Friends?
Time: 3:30 pm - 4:30 pm
Speakers: Carol Tashie, Zachary Rossetti

Hot Issues in High School Inclusion and Beyond
Time: 4:45 pm - 5:45 pm
Speakers: Douglas Fisher, Caren Sax

Friday, December 8, 2000

Discrepancies between the Spirit and Letter of Inclusion: An Overview of What Is and What Could Be for Middle and High School Programs
Time: 8:00 am - 9:00 am
Speaker: Bud Cooney

High School Inclusion: Students with Cognitive Disabilities Attend their Home Schools
Time: 8:00 am - 9:00 am
Speakers: Cynthia Levine, Patricia Knipstein

Promising Futures: Implementing Learning and Outcomes for all Secondary Students
Time: 9:15 am - 10:15 am
Speakers: Maria Timberlake, Betsy Enright

Coalition of Essential Schools: High School Restructuring
Time: 8:00 am - 10:15 am
Speakers: Mary Falvey, Lori Eshilian, Mary Jane Hibbard

Saturday, December 9, 2000

High School Inclusion: Building Inclusive Communities Through Peer Support Networks
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Heather C. Young, Anne Thomas

Making Friends in High School General Education Classes: Use of Self-Management Strategies to Initiate Social Interaction
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Stephanie Fowler, Carolyn Hughes, Susan Copeland, Penny Church-Pupke

Overcoming the Barriers to High School Inclusion
Time: 11:15 am - 12:15 pm
Speakers: Ann McKee, Susan M. Hamre-Nietupski

INCLUSIVE EDUCATION: LITERACY

Friday, December 8, 2000

The "Necessary Good:" High-Quality Balanced Literacy Instruction for All Learners
Time: 8:00 am - 10:15 am
Speakers: Leonore Pellegrino-Sino, Amy Staples

Critical Literacy and Children Labeled with Severe Intellectual Disabilities
Time: 12:15 pm - 1:15 pm
Speaker: Christopher Kliewer

Access to Literacy Activities by Students with Developmental Disabilities in Inclusive Primary Classrooms
Time: 1:30 pm - 2:30 pm
Speakers: Susan Gurry, Anne Larkin

Access Literacy: An Interactive Website to Support Literacy-Learning in Individuals with Disabilities
Time: 2:45 pm - 3:45 pm
Speakers: Amy Staples, Jane Steelman

It's Never Too Late To Learn to Read! Systematic Reading Instruction for Emergent and Early Fluent Readers
Time: 4:00 pm - 5:00 pm
Speakers: Jennifer Butterworth, Nicki McGowan, Melanie Hammond

INCLUSIVE EDUCATION: URBAN ISSUES

Thursday, December 7, 2000

Optimizing Success Through Problem Solving
Time: 10:30 am - 11:30 am
Speakers: Jane Glodoski, Marsha Staum, Patriq Dusaint, Mary Ann Fitzgerald

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Thank you to the following Official Sponsors for their support of the 2000 TASH Annual Conference!

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Join others from around the world to network at the

Roundtable Luncheon

ON THE GRAND LAWN
Thursday December 7th from 1:00-2:15 PM.

Enjoy the fresh air and breath-taking view of the pool for lunch while sharing stimulating discussions on a topic that interests you.

Tables will be labeled with suggested topics for discussion, and/or questions to stimulate thought. If you have a specific topic that you would like to discuss during lunch, please fax the following information, or include with your registration form when you send it in the mail.

I would like to participate in a discussion on: ____________________

☐ I am willing to facilitate this discussion

☐ I suggest the following person to facilitate this discussion ____________________

Participation in this event is only $10.00, which includes a delicious boxed lunch. Be sure to register when you complete your conference registration form.

Questions? Contact Kelly Nelson at 410-828-8274 x 105 or email knelson@tash.org. You can email your topic suggestions; fax them to 410-828-6706; or send a copy of this ad with your registration form!

Our thanks to Paul H. Brookes Publishing Company for co-sponsoring the roundtable luncheon.

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Moving From Self-contained Classrooms to Inclusion: A First Year Teacher's Experience
Time: 11:45 am - 12:45 pm
Speakers: Mia Belsky-Severin, Jane Glodoski

Friday, December 8, 2000

Inclusive Practices in the Urban Neighborhood?: Yes, We Do
Time: 12:15 pm - 1:15 pm
Speakers: Alice Udvari-Solner, Tayotis Caldwell, Nancy Annaromao, Matthew Cuomo, Keona Jones, Mary Beth Minkley, Jan Bloedorn

Project CHOICES: Least Restrictive Environment Initiative in Illinois - Focus on Change
Time: 1:30 pm - 2:30 pm
Speakers: Sharon Freagon, Ruth Henning, Theresa Montalbano, Ann Kremer, Bill Peters

School Inclusion and Urban Education
Time: 2:45 pm - 5:00 pm
Speakers: Wayne Sailor, Hank Edmonson, Peter A. Griggs, Donna R. Wickham, Shelly Beech

Saturday, December 9, 2000

From Lunch Buddies to Friends
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Nanho S. Vander Hart, Dolores Gribouski

LEISURE AND RECREATION

Friday, December 8, 2000

Recreation For All: Everyone's Having Fun
Time: 8:00 am - 9:00 am
Speakers: Cathryn Maddalena, Steve Youngblood

Self-Determination in Choosing Recreation and Leisure Services
Time: 9:15 am - 10:15 am
Speakers: Jeff Bassin, Susan Fleming

Enhancing Opportunities for Children with Disabilities in Youth Programs
Time: 12:15 pm - 1:15 pm
Speaker: Dale Borman Fink

Community Inclusion in Latchkey Programs
Time: 1:30 pm - 2:30 pm
Speaker: Ellen Fennick

Creating an Inclusive Early Childhood Aquatics Program
Time: 2:45 pm - 3:45 pm
Speaker: Joanne Suomi

Building Friendships and Community for Adults with Disabilities Through College Service Organizations
Time: 4:00 pm - 5:00 pm
Speakers: Amy Lynn Childre, Stacy Worden, Cynthia Chambers

MANAGEMENT ISSUES

Thursday, December 7, 2000

Effectively Managing Support Staff
Time: 10:30 am - 11:30 am
Speaker: Denise Mautz

Hilarity Therapy: Moving the Edge with Laughter
Time: 11:45 am - 12:45 pm
Speaker: John Irvin

Training Former Institution Staff in Building Community Relationships for Adults Labeled with Severe Disabilities
Time: 11:45 am - 12:45 pm
Speakers: Angela Novak Amado, Michael R. Fitzgerald

MULTICULTURAL

Thursday, December 7, 2000

An Inclusion Model for Community-Based Adult Education
Time: 11:45 am - 12:45 pm
Speakers: Erik Jacobson, Reynald Raphael

Friday, December 8, 2000

The Overrepresentation of Minority Students in Special Education Programs: Research and Practical Implications
Time: 12:15 pm - 1:15 pm
Speakers: Shanon Taylor, Michele Cervetti, Debbie Greenberg

Discrimination: Disability, Race, and Ethnicity
Time: 1:30 pm - 2:30 pm
Speakers: Carl Lashley, Peggy Terhone

Multicultural Disabilities Network
Time: 2:45 pm - 3:45 pm
Speakers: Susie Schaefer, Regina Harris, Ginger Kwan

Russian Orphans- Their Plight and Promise
Time: 4:00 pm - 5:00 pm
Speakers: William Schofield, John Richards

Saturday, December 9, 2000

Professional Preparation and Participation of Minorities in the State-Federal Rehabilitation Agencies
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Madan Kundu

PROJECT ROOTS: A Multicultural Journey
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Doug McCallum, Raquel Rodriguez, Michael Romanovitch, Christine Lynch, Barbara Morrell, Carlos Oliva

Cultural Brokering: Providing Supports for Foreign-Born Consumers
Time: 11:15 am - 1:30 pm
Speaker: Paula Sotnik

PARAPROFESSIONAL

Thursday, December 7, 2000

Strategies for Strengthening Teacher- Paraeducator Teams
Time: 10:30 am - 11:30 am
Speaker: Anna Lou Pickett

Let Every Voice Be Heard! A Qualitative Study of Paraeducators' Perspectives on Working in Inclusive Classrooms
Time: 11:45 am - 12:45 pm
Speaker: Deborah P. Goessling, James Artesani

Paraprofessional Advocacy and Training
Time: 2:15 pm - 3:15 pm
Speaker: Chiquita Morris

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Distance Delivery: A Process for Determining When a Student Requires Paraeducator Support
Time: 3:30 pm - 4:30 pm
Speaker: Patricia H. Mueller

Training: Reaching Out to Everybody
Time: 4:45 pm - 5:45 pm
Speakers: Mary Cavalier, Marjorie Kassier

PERSONNEL PREPARATION

Thursday, December 7, 2000

Research and Practice: Do Teachers Understand the Relationship?
Time: 10:30 am - 11:30 am
Speakers: Martin Agran, Sandra Alper, Kathy Davis, John J. McDonnell

Practicing What We Preach: Using Performance Portfolios in Teacher Education
Time: 10:30 am - 11:30 am
Speakers: Hollie G. Filce, Jimmie Phillips, William Sharpton, Christine Templet

Preparing Doctoral Students for Employment in Higher Education: TASH Transition Principles as Guidelines
Time: 10:30 am - 11:30 am
Speakers: Michael Brady, Diane Ryndak, Fred Spooner, Diane Baumgart

Does "All" Really Mean "All"?
Time: 10:30 m - 11:30 am
Speaker: Mary Fisher

UW- Milwaukee's Collaborative Teacher Education Program: Are Graduates Prepared to Teach Students Labeled with Significant Disabilities?
Time: 11:5 am - 12:45 pm
Speakers: Maureen Keyes, Alison Ford

Becoming A Reflective Practitioner: Preservice Teacher Preparation in the age of Inclusion
Time: 2:15 pm - 3:15 pm
Speakers: Barbara Gruber, Heather C. Young

Collaborative Outreach and Mentoring Support to Increase Diversity of Teacher Candidates
Time: 3:30 pm - 4:30 pm
Speakers: Patti Wright, Lori Goetz, Jacki L. Anderson, Ann T. Halvorsen, Catherine Foster, Sonya Martin

How Are University Faculty Infusing Information About Self-Determination in Teacher Education Courses?
Time: 4:45 pm - 5:45 pm
Speakers: Colleen Thoma, Steve Baker, Michael Wehmeyer

Saturday, December 9, 2000

Project DISCUSS - Building Partnerships Through Training
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Wendy Kalberg, Kathy Taylor, Karen Wright, Pat Osbourn

Exploring Issues Related to the Implementation of "Best Practice" by New Teachers
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Margaret Hutchins, Adelle Renzaglia

Teaching University Students About the Social Construction of Disability: Can One Course Make Any Difference?
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Julia Sherba de Valenzuela, Liz B. Keefe

Portfolio Evaluation for Inclusive Teacher Preparation
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Susan Deluke

Training Teachers to Ensure that Service Learning is NOT a Disservice for People with Disabilities
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Pamela Gent, Louis Gurecka

Teacher Preparation: Putting Principles of Positive Programming into Practice
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Marylud Baldwin, Mike Ruef

The Effects of an Intervention Package of Student Teachers' Facilitation of Communication
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Barbara Phillips, James Halle

Essential Values and Skills for Inclusion Facilitators
Time: 10:00 am - 11:00 am
Speaker: Cheryl M. Jorgensen

Promoting Person Centered Transition Planning: An Interactive Training Package
Time: 11:15 am - 12:15 pm
Speakers: Craig Miner, Paul Bates

Picking the Pros: How Parents Really Feel About Professionals As Their Partners, Collaborative Teammates, and Service Providers
Time: 11:15 am - 12:15 pm
Speaker: Susan Turben

Interagency Collaboration: The STARS Project: Building Alliances And Coalitions
Time: 12:30 pm - 1:30 pm
Speakers: Roxann Lamar, Mary Cavalier

PERSONNEL PREPARATION/ DISTANCE EDUCATION

Friday, December 8, 2000

Developing and Delivering Web-based Training in Severe Disabilities
Time: 8:00 am - 10:15 am
Speakers: Barbara L. Ludlow, Michael Duff

Experiencing Interactive Courses in Severe Disabilities over the Internet
Time: 8:00 am - 10:15 am
Speakers: Richard Kilfer-O'Donnell, Fred Spooner, Martin Agran

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POSITIVE APPROACHES

Thursday, December 7, 2000

The Behavior Management Practices of Special Education Teachers & Their Modification
Time: 10:30 am - 11:30 am
Speakers: Karena Cooper-Duffy, David L. Westling, Dean Schofield

Team Training for Positive Behavioral Support: Descriptions at State & Local Levels
Time: 11:45 am - 12:45 pm
Speakers: Jacki L. Anderson, Don Kincaid, Josh Harrower

Effective Behaviour Support in Schools: Evaluation of a Provincial Initiative
Time: 2:15 pm - 3:15 pm
Speakers: Pat Mirenda, Shirley McBride

Continuing the Fight Against Contingent Electric Shock & Other Aversive Strategies: A Legal & Clinical Analysis
Time: 3:30 pm - 4:30 pm
Speakers: Fredda Brown, Matthew Engel, Lauren Carasik

Undoing the Damage of Discrete Trial Training
Time: 4:45 pm - 5:45 pm
Speaker: Susan Deluke

Friday, December 8, 2000

Positive Approaches in Behavioral Interventions for Children with Autism
Time: 8:00 am - 9:00 am
Speakers: Marilyn Lauer, Mendy Boettcher

Without Coercion
Time: 8:00 am - 9:00 am
Speakers: William H. Ashe, Theresa Wood, Susan Yuan

The Many Faces Of Self Modeling- Applications of Video-Based Self Modeling with Challenging Behaviors and Autism, Reading and Speech, and Transitions
Time: 8:00 am - 9:00 am
Speakers: Marilyn Connor, Preston Lewis, Tom Buggey, Peter Dowrick

People First- Pushing the Paradigm
Time: 9:15 am - 10:15 am
Speaker: Bob Bowen

Paid Relationships are Important!
Time: 9:15 am - 10:15 am
Speakers: Linda Bambara, Ophelia N. Gomez, Freya Koger, Sharon Lohrmann-O'Rourke, Yan-Ping Xin

Providing Positive Behavioral Community and In-Home Supports For Youngsters with Autism - Making it Work!
Time: 12:15 pm - 2:30 pm
Speakers: Sara B. Woolf, Laurel Ross, Carolyn Scali

Positive Approaches: Taking the Leap
Time: 12:15 pm - 5:00 pm
Speakers: Michael Dowling, Anne Donnellan, Martha Leary, Anna Eliatamby, Amanda Caine, Joe Whittaker, Bonnie Forsyth

The Values and Ethics of Behavior Change
Time: 2:45 pm - 3:45 pm
Speakers: Larry Douglass, Nancy Weiss, Anne Donnellan, Jeffrey L. Strully

Facilitating Positive Behavior Support Teams
Time: 4:00 pm - 5:00 pm
Speakers: Jessica Beasley, Jayne M. Stooksbury

Saturday, December 9, 2000

Promoting Social Interaction Between a Young Child with a Disability and Children without Disabilities: A Social Intervention
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Delann Soenksen

The Impact of Positive Behavioral Support on the Quality of Life of a Child with an Autism Spectrum Disorder
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Jonathan Worcester, Glen Dunlap

Positive Approaches and Autism: Critical Thinking and Constructive Applications
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Michael McSheehan, Rae Sonnenmeier

Where Have all the Headaches Gone?
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Marilyn Bown, Aaron Hillman

Development, Field-test and Evaluation of a CD-R Prototype for Teacher Use: Tools for Nonaversive Behavior Intervention for Young Children
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Patti Campbell, Charles Campbell

Using Positive Behavioral Support to Improve School/Home Relationships
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Sara Goldberg

Creating Safe Space
Time: 10:00 am - 11:00 am
Speaker: Gail Mueller

Coping with Disability Related Stress
Time: 10:00 am - 12:15 pm
Speakers: Elizabeth A. Desousa, R. William English

Positive Approaches and Functional Communication Training
Time: 11:15 am - 12:15 pm
Speaker: Steve Baker

The Role of PBS as a Pathway to Family, School, and Community Partnerships
Time: 11:15 am - 12:15 pm
Speakers: Rachel Freeman, Wayne Sailor, Jody Britten, Amy McCart, Christopher Smith, Hank Edmonson, Donna R. Wickham, Peter A. Griggs

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RELATED SERVICES

Friday, December 8, 2000

Eligibility Criteria for Related Services: Revisiting Legal and Support Issues.
Time: 2:45 pm - 3:45 pm
Speaker: Beverly Rainforth

Motor Control and Motor Learning in Inclusive Education
Time: 4:00 pm - 5:00 pm
Speaker: Deborah Bubela

RESEARCH

Thursday, December 7, 2000

Definitions Used with Persons Having Severe Disabilities in Research: Are We Any Closer to An Understanding or Consensus?
Time: 10:30 am - 11:30 am
Speakers: Pamela Wolfe, James McAfee

Where Science Advocacy, and Values Meet
Time: 10:30 am - 12:00 pm
Speakers: Craig Kennedy, Linda Bambara

Research on Paraprofessional Supports in General Education Classes: A Case Study of a K-12 System
Time: 2:15 pm - 3:15 pm
Speakers: Michael F. Giangreco, Stephen Broer, Susan Edelman

Promoting Postive Parental Adaptation to a Child's Disability
Time: 3:30 pm - 4:30 pm
Speakers: George H.S. Singer, Leasha Barry

Valued Outcomes & Performance Indicators for Students With Deaf-Blindness
Time: 4:45 pm - 5:45 pm
Speaker: Lori Goetz

Friday, December 8, 2000

Inside Looking Out: Student Perspectives on Inclusive Education
Time: 8:00 am - 9:00 am
Speakers: Laurie R. Lehman, Valerie A. Lava

Longitudinal Research in the Community: Case Study Demonstrations of the Effects of Implementation of Positive Behavioral Support
Time: 8:00 am - 10:15 am
Speakers: Richard Albin, Glen Dunlap, Rob Horner, Wayne Sailor

Behavior States in Students Labeled with Severe and Multiple Disabilities: Descriptive Data
Time: 9:15 am - 10:15 am
Speakers: Michael D. Arthur, Jeff Sigafoos

Beyond Apples and Oranges: Issues of Meta-Analysis in Multi-Paradigm Research Synthesis
Time: 12:15 pm - 1:15 am
Speakers: Phil Ferguson, Dianne Ferguson

Achieving Inclusive Restructured Schools Through Inquiry-Based Building Leadership Teams
Time: 1:30 pm - 2:30 pm
Speakers: Elizabeth Kozleski, Dianne Ferguson

Working With Coworkers to Select Appropriate Levels of Support
Time: 2:45 pm - 3:45 pm
Speakers: Janis Chadsey, Yoshihisa Ohtake

Liberatory Theory and Paulo Friere: A Pedagogy for Inspiring Inclusion
Time: 4:00 pm - 5:00 pm
Speakers: Paula M. Kluth, Jacqueline Thousand

Saturday, December 9, 2000

The Function of "Virtual" Community in the Creation of a Community Life: The Emerging Role of the Internet in Community Inclusion
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Joanna Royce-Davis

Using a Webcam as an Alternative Delivery System: "Any Time, Anywhere Consultation Through Technology"
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Emily Watts, Jo Robertson

"OOS Sensei, Oos Sempai!": Lessons on Inclusion from a Martial Arts School
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Shridevi Rao

"I Know How To Do": Stories of Choice, Control, and Power
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Phil Smith

Behaviour States in Students: Further Analyses
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Michael D. Arthur

The Service Coordination Scale
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Todd Case

The Nature and Sources of Educators' Comfort and/or Concerns with Inclusion
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Diana Lawrence-Brown

Evaluating the Processes and Outcomes of an Inclusive School Program
Time: 10:00 am - 11:00 am
Speakers: Stacy Dymond, John Kregel, Martha Nigrelli

Building a Collaborative Support System: A School Task Force's Role in Systemic Reform to Support all Students
Time: 11:15 am - 12:15 pm
Speakers: Denise Clark, Diane Ryndak

The Family Network Project: Providing Positive Behavioral Support to Families from Underserved Communities
Time: 12:30 pm - 1:30 pm
Speakers: Bobbie J. Vaughn, Lise Fox, Glen Dunlap

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SELF-DETERMINATION

Thursday, December 7, 2000

Using Self-Determination Principles to Plan for Children of Adolescents
Time: 11:45 am - 12:45 pm
Speaker: Ellen Cummings

YOUTHSPEAK: Promising Futures for ME!
Time: 2:15 pm - 3:15 pm
Speakers: Janet May, Bonnie Robinson, Elijah Steward, Deborah A. Gilmer

Are Teachers Determined to Teach Self-Determination? Results of Contemporary Research
Time: 3:30 pm - 4:30 pm
Speaker: Thomas Holub

Peer Counseling for People Labeled with Mental Retardation and Cognitive Impairments
Time: 3:30 pm - 4:30 pm
Speaker: Joe Meadours

Self-Determination and Young Adults Who Are Deaf-Blind
Time: 4:45 pm - 5:45 pm
Speakers: Susie Morgan, Jamie McNamara

Teachers' Facilitation of Self-Determination in Secondary Students with Moderate Development and Disabilities: An Initial Case Study
Time: 4:45 pm - 5:45 pm
Speakers: Maureen E. Angell, Stephanie Kouzoukas

Friday, December 8, 2000

2 + 2 = 5 When is Self Determination Greater Than the Sum of Its Parts?
Time: 8:00 am - 9:00 am
Speaker: Marilyn Kuna

Self Determination-Developing an Organizational Culture
Time: 8:00 am - 9:00 am
Speaker: Ruth Siegfried

Shake, Rattle, and Roll: Creating Change Through Self-Determination
Time: 9:15 am - 10:15 am
Speakers: Ann Marie Campbell, Kathy Sykes, Barbara Prince, Carolyn Morgan, Deborah Robinson

"Reaching My Own Greatness"- A Self-Determination Program that is Activities Based
Time: 12:15 pm - 2:30 pm
Speaker: Donna Lowary

Thriving in My Community: a Plan for Independence, Support and Belonging
Time: 2:45 pm - 3:45 pm
Speakers: Gail M. Godwin, Linda Essenmacher, Kathy Vecchioni, Ellen Franks, Donald Row

Vermont Self-Determination Project: Families, Self-Advocates, and Professionals Working Together
Time: 4:00 pm - 5:00 pm
Speakers: Kim Daniels, Phil Smith, Patty Grassette

Saturday, December 9, 2000

Leadership Today: Partners in Effective Decision-Making
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Sandra Mak

Philadelphia's Self Determination Initiative
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Diane Lackey, Ann Marie Campbell, Liat Richardson, Octavia Green

Three Required Components of Successful Transition Processes According to Students with Disabilities
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Thomas Neuville

Believe in Yourself: The Road to Becoming a Self-Advocate
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Margaret Stout, Sheri Glasser

Of the People, By the People, For the People: Be an Active Part in Your Government
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Lois Rogers

The Self-Determination Network
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: David Guare, David Wyher

The Road to Freedom: Choice Theory, Reality Therapy and Self-Determination
Time: 10:00 am - 11:00 am
Speakers: David P. Sansone, Robert Renna

Self-Direction, Self-Determination and Care Accreditation
Time: 10:00 am - 11:00 am
Speaker: Dale Dutton

Self-Determination Synthesis Project: Final Report
Time: 11:15 am - 12:15 pm
Speakers: Wendy M. Wood, David W. Test, Diane Browder

Realizing My Potential Through Communication, Self-Determination & Self-Advocacy
Time: 11:15 am - 12:15 pm
Speakers: Jennifer Paige Seybert, James Seybert, Kendall Seybert

Using Self-Management to Improve Study Skill Performance of High School Students with Extensive Support Needs in General Education Classrooms
Time: 11:15 am - 12:15 pm
Speakers: Susan Copeland, Stephanie Fowler, Carolyn Hughes

BRIEFS: A Conceptual Model For Empowering Persons and Families
Time: 12:30 pm - 1:30 pm
Speakers: R. William English, Elizabeth A. Desousa

SEXUALITY

Thursday, December 7, 2000

Sexuality? Intimacy? Meeting the Sensual Needs of Individuals Labeled with Severe Disabilities
Time: 2:15 pm - 3:15 pm
Speaker: David Hingsburger

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An Honest Dialogue about Embracing the Sexuality of Indivi-duals with Significant Disabilities: Implications for Future Directions

Time: 3:30 pm - 4:30 pm
Speakers: Wanda J. Blanchett, Pamela Wolfe

Personal SPACE: A Violence Prevention Program for Women

Time: 4:45 pm - 5:45 pm
Speakers: Catriona Johnson, Susan Holland, Mary Ann Carmody

Friday, December 8, 2000

The Forgotten Educational Domain: Strategies for Successful Socio-Sexual Programs for Individuals with Disabilities

Time: 8:00 am - 10:15 am
Speakers: Pamela Wolfe, Wanda J. Blanchett

SPECIAL HEALTH CARE NEEDS

Friday, December 8, 2000

Continuing Inclusion: When Children Have Special Health Care Needs

Time: 1:30 pm - 2:30 pm
Speakers: Arlene Lockenwitz, Cynthia Levine, Patricia Luce

Saturday, December 9, 2000

Using a Consensus Panel Approach to Address Systemic Issues Associated with Dual Diagnosis

Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Dina McFalls, Carol Persons

SPIRITUALITY

Friday, December 8, 2000

Exploring the Role of Spirituality in our Lives

Time: 12:15 pm - 1:15 pm
Speakers: Alan Berger, Maureen Keyes, Kathleen Gee

Embracing Different Abilities: A Spiritual Path

Time: 1:30 pm - 2:30 pm
Speakers: Kathryn O'Connell

Peacemaking, Spirituality and Community: Honoring the Journey

Time: 2:45 pm - 5:00 pm
Speakers: Craig A. Michaels, Denise L. Ferrara

STUDENTS WHO SEVERLY CHALLENGE SCHOOLS, BUT WHO DON'T HAVE LABELS OF SEVERE DISABILITIES

Thursday, December 7, 2000

Alternatives to Due Process to Affect Change for Your Child

Time: 2:15 pm - 3:15 pm
Speakers: Donna R. Wickham, Nancy Thomas, Peter A. Griggs

Including Even Those Who "Don't Wanna" or "Don't Care": Classroom Structures to Maximize Learning for All Students

Time: 3:30 pm - 4:30 pm
Speaker: Linda Rammler

Views from the Inside: A Student Who Has Severely Challenged Schools Relates His Experiences in Terms of What Has Gone Right and What Has Gone Wrong With His Education

Time: 4:45 pm - 5:45 pm
Speakers: Timothy Gionfriddo, Linda Rammler, Mark Partin

TEACHER DEVELOPMENT/ PREPARATION

Thursday, December 7, 2000

Reforming Teacher Education to Support Inclusion

Time: 11:45 am - 12:45 pm
Speakers: Amy G. Dell, Orah Raia

Friday, December 8, 2000

How to Evaluate Models and Effectiveness of Professional Development

Time: 12:15 pm - 1:15 pm
Speaker: Melissa Price

Creative Use of Icebreakers to Promote More Effective Professional Development

Time: 1:30 pm - 2:30 pm
Speaker: Janice Payne

Powerful Teaching: Competent By All Means - A Framework for Successful Education and Transition Outcomes

Time: 2:45 pm - 3:45 pm
Speaker: Charles Fitzgerald

Project WINning Team: A Statewide Professional Development Program for all Personnel in Inclusive Schools

Time: 4:00 pm - 5:00 pm
Speakers: Toni Stricker, Gail Wilkins, Cathy Henson

TRANSITION

Thursday, December 7, 2000

Case Studies in Transition: Cross-Project, Cross-Agency Outcomes (for students labeled with severe disabilities)

Time: 10:30 am - 12:45 pm
Speakers: Karen Zimbrich, Maria Paiewonsky

Negotiating Job Training Sites

Time: 11:45 am - 12:45 pm
Speakers: Melissa A. Brown, Jayne M. Stooksbury, Nicki McGowan

Transition Service Integration Model: A Proven Strategy for Seamless Transition

Time: 2:15 pm - 3:15 pm
Speaker: Nicholas J. Certo

Transitioning to Tomorrow's Hopes and Dreams

Time: 3:30 pm - 4:30 pm
Speakers: Kay Branz, Jane Doyle, Mary Zubek

If You Can Do It In New York City, Then You Can Do It Anywhere: Post Secondary Transitions and Inclusion: Opportunities for More Faces in New Places

Time: 4:45 pm - 5:45 pm
Speaker: Gail Ray, Vaulda Kendall-Browne, Mayra Rodgiguez, Sharon Williams

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Friday, December 8, 2000

Postsecondary Education Options For All Students
Time: 8:00 am - 10:15 am
Speaker: Debra Hart

Subtleties of Person-Centered Transition Planning: Mastery Through Process and Accomplishment Extending the Boundaries of Collaboration
Time: 9:15 am - 10:15 am
Speakers: Denise L. Ferrara, Craig A. Michaels, Gerardo Delgado, Maria Delgado, Marcos Delgado

Successful Transitions Following Inclusion
Time: 12:15 pm - 1:15 pm
Speaker: Mark Stuart

An Overview of Transition Assessment: A Person-Centered Approach to Supporting the Student Choices for Life
Time: 1:30 pm - 2:30 pm
Speakers: Mary F. Held, Colleen Thoma, Steve Baker

School and Agency Partners in Development of An Inclusive School-To-Work Mentorship Program
Time: 2:45 pm - 3:45 pm
Speakers: Peg Lamb, Teri Thompson, Cynthia Wright

Holding On and Letting Go: Preparing for Transition to Adult Life
Time: 4:00 pm - 5:00 pm
Speakers: Lewis Persons, R. William English, Elizabeth A. Desousa

Saturday, December 9, 2000

Enhancing Transition Services for Students Who are Deaf/Hard of Hearing: Moving Beyond Transitional Approaches
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Kourtland R. Koch, Catherine Witty

Teacher Perceptions on Best Practices in Transition
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Mary Ann Beckman, Laura Owens-Johnson

Evaluating Entry Level Workers in Supported Employment: The Job Observation and Behavior Scale
Time: 7:30 am - 10:00 am (Poster Session)
Speakers: Howard Rosenberg, Michael Brady

Transition Planning from School to Adult Life: Content Analysis of Transition Plan Meetings in the Province of Quebec
Time: 7:30 am - 10:00 am (Poster Session)
Speaker: Georgette Goupil, Marc Tasse, Nathalie Garcin

Getting From Here to There: Higher Education for People with Disabilities
Time: 10:00 am - 11:00 am
Speaker: William Picard

Collaboration Between Public Schools and Institutions of Higher Education to Facilitate Choice in the Transition Years
Time: 10:00 am - 11:00 am
Speakers: Caroline Dipipi, Edward Grasso

Buying Transition Services from Adult Service Providers: True Interagency Collaboration
Time: 11:15 am - 12:15 pm
Speaker: Laura Owens-Johnson

Developing Seamless Transition Plans
Time: 12:30 pm - 1:30 pm
Speakers: Jayne M. Stooksbury, Melissa A. Brown, Melanie Hammond

WHOLE SCHOOL CHANGE

Thursday, December 7, 2000

Perspectives on Whole School Reform
Time: 2:15 pm - 3:15 pm
Speaker: J. Michael Peterson, Richard A. Villa, Cheryl M. Jorgensen, Cathy Hilde

Connecting Inclusive Education to Whole School Reform: Work in Progress in Massachusetts, Florida, and California
Time: 3:30 pm - 4:30 pm
Speakers: Bill Henderson, Diane Ryndak, Theresa A. Ward, Douglas Fisher, Nancy Frey, Ric Reardon

An Inclusive Approach to Whole School Reform
Time: 4:45 pm - 5:45 pm
Speakers: J. Michael Peterson, Rich Gibson, Kim S. Beloin, Candee Basford, Barbara McKenzie, Nancy Frey, Bill Henderson, Cathy Hilde, Cheryl M. Jorgensen, Diane Ryndak, Theresa A. Ward, Richard A. Villa, Ric Reardon

2000 TASH Conference Committee

Anne Smith
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Donna Gilles
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Liz Obermayer
Patti Scott
Tia Nelis

March for Justice

We're Voting for Our Lives!

NEW DATE

Tuesday October 3, 2000 - 12:00 Noon

U.S. Capitol grounds at Upper Senate Park (North side of the Capitol)
Washington, DC

Come to Washington and join thousands of civil rights advocates to support the Americans with Disabilities Act (ADA) and the civil rights of ALL Americans.

This fall, the United States Supreme Court will be hearing arguments in the case of *Garrett v. University of Alabama*, which calls into question the constitutionality of the ADA. This is not just a case about disability rights - it is about the civil rights of all Americans. There are no guarantees in life, and anyone may find themselves facing the injustice of discrimination by an employer or lack of access, because of a disability or even a serious illness such as cancer, asthma, or HIV/AIDS. Without the protections that the ADA provides to guard against injustices in the workplace and community, everyone in America is faced with the threat of losing their civil rights.

The **March for Justice** will take place just 35 days before the election of the next President of the United States. The next President is expected to appoint several new Supreme Court Justices during his term. The decisions that the next group of Supreme Court Justices will hand down will have an effect on the civil rights of all Americans for generations to come. We need to make sure that the Presidential candidates are aware that we will be voting with our hearts and minds in favor of justice for all!

Make plans now to be in Washington D.C. on the first Tuesday in October – following the opening day of the Supreme Court session – to join with other advocates for justice from across the country. With our combined voices, we will send a loud and clear message to our elected officials and candidates that we are "VOTING FOR OUR LIVES" in this election.

So, come to Washington DC on October 3 or participate in a local event and do all you can to let our message be heard.

And remember!!!

Be sure to encourage your family, neighbors, and friends to get out and VOTE FOR THEIR LIVES on November 7. (ARE YOU REGISTERED TO VOTE?)

Founding Sponsors of the
March For Justice: We're Voting for Our Lives!

American Association of People with Disabilities - AAPD
ADAPT
Consortium for Citizens with Disabilities-CCD
Disability Rights Education and Defense Fund – DREDF
Disability Rights Center
Justice for All
Leadership Conference on Civil Rights
National Association of People with AIDS
National Association of Protection and Advocacy Systems – NAPAS
National Council on Independent Living – NCIL
National Parent Network on Disabilities – NPND
TASH: Disability Advocacy Worldwide

Don't Miss TASH's First Ever

Silent Auction Event

When: December 7 and 8 ONLY

Where: Exhibition Hall, TASH 2000 Annual Conference

We are collecting unique, one-of-a-kind gift items, autographed photos and posters, conference registrations, hotel stays, goodie baskets, books and CDs, consulting services and more items than we can enumerate here to auction off to the highest bidder! TASH is delighted to announce its first Silent Auction Event to help raise funds for the TASH Conference Scholarship Fund.

Proceeds from this Fund assist people with disabilities, parents and other family members to attend future TASH conferences. Donations have been received from TASH chapters around the country, local merchants in the Miami Beach area, sports teams, hotels, individual donors and many others including:

Anchorage Hilton ◦ Baltimore Orioles ◦ Blockbuster Video
Center for Community Inclusion, UAP - University of Maine
Justin and Yoshiko Dart ◦ Giant Foods
Grillfish Restaurant (Miami Beach) ◦ Hard Rock Café (Miami)
Jacksonville Jaguars ◦ Rammler & Wood Consultants
Reno Hilton ◦ Reno-Sparks Convention & Visitors Authority
Sheraton Boston ◦ Van Gogh Music
Walt Disney Company ◦ The Wolfsonian-FIU Museum

and there will be goodie baskets and other merchandise representing the following states and regions, courtesy of the following TASH chapters:

Cal-TASH ◦ Delaware-TASH ◦ Iowa-TASH ◦ Missouri-TASH
Texas-TASH ◦ Washington-TASH

Donations are coming in daily! Why not join your friends and colleagues and help to ensure that the invaluable information and phenomenal networking opportunities that are cornerstones of TASH annual conferences will be available to that many more people in the future? Donate a silent auction item today!

For more information, or to obtain a donation form,
contact Priscilla Newton, Director of Marketing, at 410-828-8274, ext. 102
or send an e-mail to pnewton@tash.org
Donors will receive special recognition in the official conference program and on TASH's web site.

And don't forget -- A portion of your donation may be tax deductible!*

*Please consult appropriate IRS Guidelines

Bring the Entire Family to the conference!

▽ ▽ ▽

This year there are a variety of programs available at the conference for kids of all ages! Of course, the location is beachfront, has an incredible pool, and has direct access to a boardwalk that stretches for miles along Miami Beach.

TASH will be operating the highly successful and fun childcare program for children ages 1 month – 13 years in cooperation with KiddieCorp as we have done in years past. The charge is $2.00 per hour per child, and there is a 3 hour minimum block. Pre-registration is required. The registration form appears on the next page. If you are interested in information about this program please check the box on the registration form or call 1-800-482-8274.

In addition, the Fontainebleau has an extensive Resort Activities Program, for children ages 5-12 and a teens 13-17, who are able to swim without the assistance of a floatation device. Rates vary with activities. For more information contact the Kid's Corner at the Hilton , (305)538-2000 x 3445

TASH Child Care Registration Form

Please fill out this form and return to TASH at the address listed below, NO LATER THAN 11/15/00. *MAKE CHECKS PAYABLE TO TASH.* A confirmation letter with release forms will be sent to you once payment is received. **Please send in a paragraph with this form about your childs interest and needs.** Please indicate the age each child will be on December 1, 2000.

CHILD'S NAME____________________ **AGE:**_____ **SEX:**____ **BIRTHDATE:**__________
CHILD'S NAME____________________ **AGE:**_____ **SEX:**____ **BIRTHDATE:**__________
CHILD'S NAME____________________ **AGE:**_____ **SEX:**____ **BIRTHDATE:**__________

Rates are $2.00 per hour per child with a consecutive three hour minimum period required.

Day	Hours of Operation	Specific Hours of Care Requested	Number of Children	TOTAL Per Day
Wednesday 12/6/00	9:00-4:30			$
Thursday 12/7/00	7:45-5:45			$
Friday 12/8/00	7:45-5:45			$
Saturday 12/9/00	7:45-1:00			$
		Non-Refundable Reg. Fee $5.00		$
		GRAND TOTAL		$

Payment: **Check*____ *Visa*____ *Mastercard*____ *Discover*____
*Card#*______________________________*Exp. Date*__________

The Child(ren) named above will be released ONLY to the person(s) signing this application and the following additional person(s):

Father/Guardian Full Name:____________________ Signature:______________
Mother/Guardian Full Name:____________________ Signature:______________
Address:________________ City:____________ State:________ Zip:________
Home Phone#:__________________ Daytime Phone#:__________________

Mail this completed Registration Form and FULL PAYMENT, payable in U.S. Funds,
NO LATER THAN 11/15/00 to TASH 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204.

For Office Use Only
Amt. Recvd._____ Amt. Due_____ On Timeline______ In Comp.______

2000 Conference Registration Form

(Esto forma es disponible en español por contacto 1-800-482-TASH (8274) or 410-828-8274 or registration@tash.org)

2000 TASH Conference

moving the edge

Miami Beach, Florida - December 6-9th

Instructions for filling out this form:

1. **Fill out one form for each person attending**
2. **Fill out all information requested on the form**

Make Checks Payable to: TASH

Mail: TASH, 29 W. Susquehanna Avenue,
Suite 210, Baltimore MD 21204
Fax: (410) 828-6706
Questions? Call: 1-800-482-TASH (8274) or 410-828-8274
Email: registration@tash.org **Website:** www.tash.org
TDD: (410) 828-1306 **Federal Id # 51-0160220**

TASH Office Use Only

Org ______________
Cust ______________
Reg ______________
Init ______________

Conference Participant:
First Name: ______________________ Last Name : ______________________
Preferred Badge Name: ______________________ Organization: ______________________
Street Address: ______________________ City / State: ______________________
Postal Code: __________ Country ______________ This address is [ ] home [ ] work [ ] school [ ] other ________
Work Phone: ______________________ Home Phone: ______________________
Fax: ______________________ E mail: ______________________
Please list your interest areas or occupation (for example: advocate, administrator, teacher, etc..)

Billing Address: ______________________
Billing Contact (Name): ______________________ (Phone): ______________________

Accessibility and Accommodations

You are responsible to make your own reservations for hotel accommodations. The information on this form applies only to participation in the conference sessions and activities. Please make all requests such as interpreting and materials in Braille by November 10th to ensure fulfillment of your request. Any requests made after that date cannot be guaranteed.

☐Sign Language Interpreter *Please indicate dates and times needed*: ______________________

☐Sesión albedrío ser ofrecido con Español interpretación. Seria interesado en más información en este servicio.

☐Please list ADA accommodation needs (Large print, Braille etc.) ______________________

☐Please specify your dietary needs: ______________________

☐Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)

☐Roommate Referral Program

Registration Costs (must be drawn on a U.S. Bank)

Registration Category – TASH International Members

[ ]	Individual Registrant	$229
[ ]	Family Member of a Person with a Disability	$ 69
[ ]	Person with a disability	$ 69
[ ]	Personal Assistant *	$ 50
[ ]	Student	$169
[ ]	One day only ☐Thurs ☐ Fri ☐Sat	$139

Current TASH Member # ______________

(**Personal assistants must register at the same time as individual for whom they are providing support to attend conference activities*)

Registration Category – TASH Chapter Only or Non-Members

[ ]	Individual Registrant	$359
[ ]	Family Member of a Person with a Disability	$145
[ ]	Person with a disability	$145
[ ]	Personal Assistant (**see note above*)	$ 50
[ ]	Student	$ 259
[ ]	One day only ☐Thurs ☐ Fri ☐Sat	$199

1. Enter Registration Cost $ ______________

Registration Discounts

Early bird Registrations (received with payment by September 30, 2000)	Subtract $20 per registrant for early bird and team discount if applicable.	
Team Discounts: • Groups of 5 or more registering for full conference (all registrations must be sent in at the same time) • A direct support staff is registering with a self-advocate • Two or more members of the same school team are registering together (ie: a special educator and a regular educator, or a regular educator and a paraeducator)	**2. Subtract Discount Here**	$ - ____________
Round Table Networking Luncheon — Thursday 1:00–2:15 PM *(you must purchase a ticket in advance, and please be sure to fill out any special diet requests if applicable)*	**3. Add Luncheon Fee Here** $10.00 per person	$____________
After November 17, 2000 registrations will be on-site only and a $40.00 late fee must added. To ensure that your registration process goes as smooth as possible and to save money, we encourage you to register early. If you do register on-site you must bring this form and method of payment with you at time of registration.	**4. Enter Late Fee Here** (if applicable)	$____________

Enter Total Conference Registration Here (Total from 1-4 above) $____________

Pre-Conference Workshops 9:30 AM–4:00 PM (registration is in addition to the conference fees) Wednesday, December 6th

See list of workshops on page 3 of the brochure

First Choice Tech # ____________

Second Choice Tech #____________

☐ Special Symposium — $65.00 for TASH Members $95.00 for non-members

☐ I plan to attend the TASH Chapter Leadership Day

• TASH Member	$55.00
• Non-Member	$85.00
• Individual w/a disability/ Family Member of a person with a disability	$40.00

Enter Pre-Conference Fee Here $ ____________

☐ Yes I would like to make a donation to support self-advocates/parents to attend the conference $5_____ $10_____ $15_____

TASH MEMBERSHIP:

☐ I am renewing my membership now #__________

☐ I am becoming a member now

If you are joining with 3 or more people from the same agency/organization/school take $20 off each person's applicable rate (must be in the same envelope)!

New and Renewing Members please select membership type

	International & Chapter	International Only	Chapter Only
General	$103	$88	$33
Associate Membership *Annual income less than $25,000 or if full membership presents a financial hardship*	$60	$45	$20
Family Discount *Additional members joining from the same household*	$51.50	$44	$16.50
Organizational	$230	$200	$70
Lifetime	$1000	N/A	N/A

Add $10.00 for postage costs for members in Canada and $25.00 for members outside the U.S. and Canada $ ____________

Enter Total TASH Membership Fee Here $ ____________

TOTAL AMOUNT ENCLOSED: $ ____________

Payment Terms: Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from all requests for refunds that are received before Nov 1, 2000. No refunds will be given for cancellations after that date. $25.00 fee for returned checks or unauthorized charges.

☐ Check Enclosed ☐ Purchase Order / State Voucher no. ______________

☐ Visa ☐ MasterCard ☐ Discover Name on Card: ______________________

Card Number: ______________________

Signature: ______________________ Exp. Date: ______________________

Our thanks to the 2000 Conference Reviewers who donate countless hours reviewing proposals and formulating the session schedule.

We couldn't do it without you!

Sue Dotson
Mary Hayden
Debbie Gilmer
Don Kincaide
Alan Factor
Michael Bailey
Pat Mirenda
Marti Snell
Don Cardinal
Joe Wykowski
John Lian
Patti Scott
Lisa Sonnenborn
LeighAnn Davis
Elizabeth Erwin
Valerie Lava
Mike Callahan
Cary Griffin
John Butterworth
Barb Buswell
Lynda Atherton
Dohn Hoyle
Mayer Shevin

Donna Lehr
Liz Healey
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Carol Quirk
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Alan Berger
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Jill Green
Linda Rammler
Debbie Gilmer
Pat Rogan
Janis Chadsey

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Priscilla Newton, *Editor*

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MEMBERSHIP INFORMATION

Name:____
Address:____________________ City/State/Zip:____________________
Telephone: (   ) ____________ Fax: (   ) ____________ E-mail: ____________
Is the above your ☐ work address ☐ home address ☐ other____________________

Please Check Appropriate Categories (not more than three):
( ) Administrator/Adult Services
( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
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( ) Behavior Specialist
( ) Case Manager
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( ) Educator/Teacher (K-12)
( ) Government
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional/Public Policy Advocate
( ) Professor/Instructor-College/University
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
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( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
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( ) Supported Employment
( ) Other

Moving? *Please notify TASH of your new address.*

General Membership (individual) $103*
Organization/Subscription (all organizations, schools, libraries, universities, etc. must use this category) $230*
Associate Membership (for people having an annual household income of $25,000 or less, and for whom payment of the full fee would present a financial hardship) $60*
Lifetime Member $1,000

Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

Group Discount Rate (When three or more individuals from the same organization join as International/Chapter or International Only members at the same time — Save $20 per membership!)

Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information in the next column.

( ) Mastercard ( ) Visa ( ) Discover
Card Number____________________ Expiration Date________
Signature________________________________

( ) I would like to spread my payments out. Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.

*These prices entitle you to both International and Chapter memberships for International or Chapter only prices, please call us at 1-800-482-8274.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone:410/828-8274 Fax: 410/828-6706

TASH
29 West Susquehanna Avenue
Suite 210
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Phone: 410/828-8274
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TASH Newsletter

VOLUME 26 ISSUE NUMBER 10 OCTOBER 2000

International Perspectives

Inside this issue: Augmentative/Alternative Communications in Guatemala • *Growing Up with a Disability in Iceland* • **Early Childhood Care and Development Worldwide**

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

TASH wishes to acknowledge the generous support of our newest lifetime members

Community Developmental Services - Barre, Vermont
Ming-Gon John Lian - Pokfulam, Hong Kong
Elizabeth Obermayer - Towson, Maryland
Robin Wood - Wallingford, Connecticut

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.

Please see page 3 of this Newsletter for new lifetime member rate.

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2000 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Dan Dotson, Coordinator of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:ddotson@tash.org
- **For information on marketing and promotions, permission and reprints, or newsletter submissions and advertising, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

Support TASH whenever you shop online!

Shop online through igive.com or greatergood.com TODAY!

We've made it convenient and simple for you to shop online ***and*** support the work of TASH at the same time. Your purchases will cost no more but TASH will benefit!

By shopping through igive.com or greatergood.com, two popular online shopping services that represent hundreds of retailers such as Amazon.com, Barnes & Noble, The Gap, Disney Store, Gift Baskets.com, J. Crew, Nordstrom, Petsmart, J.C. Penney and scores of others, you can have the ease and savings that come with shopping online, and the knowledge that **up to15% of every purchase you make will be donated to TASH!**

Best of all, it's FREE to shop via igive.com and greatergood.com! Your purchases will cost exactly what they would have if you had gone directly to the merchant's web site.

HOW DO I SIGN UP?

It's as easy as 1, 2, 3!

1. Go to igive.com or greatergood.com on the web.
2. Follow the simple instructions to register as a new member. Before shopping, make sure to identify TASH as the organization you wish to support.
3. Click on any of the hundreds of websites to shop as you normally would!

Up to 15% of your total purchases will be donated to TASH.

Other great deals available to you as a member of igive.com and greatergood.com include

Discounts from select stores

Free shipping offers

An entire online mall filled with brand name merchants ready to serve you!

••••••••••

Shop at **igive.com** or **greatergood.com** 24 hours a day, 7 days a week! Remember to go to **igive.com** or **greatergood.com** first to access your merchant of choice from these sites.

Need help? Questions? Call us at 1-800-482-8274, ext. 106 or send an e-mail to info@tash.org

Supporting TASH is just a click away and as easy as shopping online!

DON'T DELAY!

Become a lifetime member of TASH today!

A new rate goes into effect January 1, 2001!

Have you been considering becoming a lifetime member of TASH, but haven't gotten around to doing so? The price of a TASH Lifetime Membership has not increased since the inception of this membership option almost twenty years ago. Lifetime memberships are currently priced at $1,000. This cost can be spread over multiple payments if you choose. **Once you are a lifetime member, you never need to pay TASH membership dues again.** Lifetime members are recognized in the TASH *Newsletter* and in each year's conference program.

The TASH Executive Board has approved a price increase for Lifetime Memberships from the current rate of $1,000 to $1,300, effective January 1, 2001. We hope you will take advantage of the opportunity to become a Lifetime Member of TASH at the current $1,000 rate. You can become a lifetime member by phone (call 1-800-482-8274, ext. 0) or on our web site (www.tash.org). To find out more or to arrange to pay for your membership over several payments, call Rose Holsey at 1-800-482-8274, ext. 100 or send an e-mail to rholsey@tash.org.

From the Executive Director
BY NANCY WEISS

TASH Meets with President Clinton -- Presents our Concerns Related to Federal Disability Policy

On Friday, October 27th, a small group of disability advocates and I met with President Clinton to discuss measures that Clinton could take in his final days in office to improve services in the community and reverse the institutional bias of federal long-term care policy.

Also in attendance were Justin Dart, Jr., of Justice for All, Mike Auberger and Barbara Toomer of ADAPT, Mike Oxford and James Billy from the National Council on Independent Living (NCIL) , Debbie Kaplan from the World Institute on Disability, Bobby Silverstein of the George Washington University School of Public Health, Andy Imparato from AAPD, and Paul Marchand representing The Arc and Council for Citizens with Disabilities (CCD).

In attendance from the White House, in addition to the President, were: Chief of Staff John Podesta; Mary Beth Cahill, Assistant to the President and Director of Public Liaison; Chris Jennings, Deputy Assistant to the President for Health Policy; and Jonathan Young, Associate Director for Disability Outreach. Bob Williams, Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy represented the Department of Health and Human services. Tim Westmoreland, Director of the Center for Medicaid and State Operations represented the Health Care Financing Administration.

The President opened the meeting by announcing a new rule that had just been posted for a 60 day comment period and would be finalized before the end of the Administration. This rule would expand states' flexibility in disregarding income and resources for purposes of Medicaid eligibility determinations. This rule change will promote the use of home and community-based services and supports. Chris Jennings estimated that this enhanced Medicaid state option would provide an additional $960 million in Medicaid benefits over five years.

The President then updated the group on the current state of budget negotiations and stated his continuing hope that this administration will be able to get the Family Opportunity Act passed and $50 million allocated for systems change grants for Olmstead implementation. The purpose of these grants would be to conduct intensive outreach efforts to educate people with disabilities about the home and community-based options currently available to them; create new one-stop centers that streamline application and eligibility processes for home and community-based services and supports; and identify, develop, and implement strategies to modify state policy that results in the unnecessary institutionalization of people with disabilities. As a condition of receiving funds, states would actively involve people with disabilities and their families in the development of programs enabling people with disabilities to choose where they want to live and receive supports. To the delight of participants, Clinton referred to these systems change grants as "MiCASSA grants."

Justin Dart opened the meeting on behalf of the advocates, thanking the President for his ongoing leadership in support of the disability community and for taking the time to meet with disability advocates at this critical juncture in the legislative process. He emphasized the importance of addressing the institutional bias and giving people real choices and real options in the community so they are not forced into nursing homes or institutions.

Mike Auberger addressed the President next and spoke about the many things that could be done administratively to begin to address the institutional bias in the Medicaid program. Auberger encouraged the President to act on as many of these administrative changes as possible before leaving office. Debbie Kaplan emphasized the importance of personal assistance services and the need to promote some of the best practices that are being demonstrated at the state level.

I addressed the President after Ms. Kaplan. I described TASH and told the President that our legislative priorities included passage of MiCASSA and enforcement of IDEA: An important point that I stressed was that enforcement of this important bill was often left unfairly on the shoulders of parents. I also emphasized the importance of the Family Opportunity Act to give families with children with disabilities the ability to work and maintain critical health coverage for their children. I stated that parents are often in the position of having to refuse jobs or promotions to assure that their income does not make them ineligible to receive Medicaid coverage for their child with a disability, and are sometimes forced to place their children in institutions because no other options exist to assure critical health care. I stressed that families are not looking for a handout, but rather for the opportunity to buy into Medicaid as their salaries increase.

TASH's important message that I communicated to the President is that people with severe developmental disabilities no more want to, or need to live in institutions than does anyone with a physical disability or than does anyone else, including all non-disabled individuals as they age. I told the President that it was not just the people sitting around the table that day who were concerned about

Continued on page 14

moving the edge
2000 TASH Conference
Miami Beach, Florida • December 6-9th

Your Conference Revenue Dollars at Work

BY DENISE MARSHALL
Director of Meetings and Information Resources, TASH

There are many reasons why attendees come to TASH conferences: dedicated members who never miss, knowledge-seekers, value-based activists, social networkers, and of course, those who want to mix business with pleasure and visit the location! On the surface it is easy to focus on the event itself as the end to the means, but TASH members know that it is really just a starting point for rejuvenating personal energy, individual and professional networking, for giving folks the tools they need to cultivate social change. Few realize though, there is another outcome going on behind the scenes: the impact registration and accommodation dollars have in enabling TASH to raise consciousness and make tangible change in the cities and at the hotel properties at which we hold our events.

TASH's annual conference brings over half a million dollars in revenue through rooms sales, food and beverage costs, and outlet sales (in the giftshops, and restaurants) to the host city.

Five years ago TASH started to move the conference to different locations throughout the United States, rather than staying with a rotation of Chicago, Washington, D.C., and San Francisco exclusively. Overall, this change has had a positive impact on the association by strengthening or re-energizing local chapters and enabling people to attend the conference for the first time (some of whom could not previously do so because of travel costs).

What we did not foresee was the impact we would have on the destinations. TASH brings over $500,000 in revenue through rooms sales, food and beverage costs, and outlet sales (in the giftshops, and restaurants) to the host city. Revenue speaks, and we have been using it to pursue quite interesting and productive conversations!

Here are a few examples. Last year, after a long absence, we held the 1999 convention in Chicago. Attendees found that a hotel which seemed just fine in 1993 was not up to the 2000 standards we have come to expect and demand to ensure equal access for all. A conference the size of ours needs to book our convention many years in advance, and we had already rebooked The Chicago Hilton and Towers for 2003. In the spirit of TASH, rather than despairing we looked at this as an opportunity. Several TASH members met with hotel representatives on-site, and Nancy Weiss, TASH's Executive Director, and I worked with the general manager of that property in the months that followed. Here are some of the major items that the Chicago Hilton and Towers has contractually agreed to do prior to the conference in 2003:

○ The Northwest Exhibit Hall will be renovated, ensuring that the slope of the ramp is one foot per inch of rise, as required under the Americans with Disabilities Act.

○ In addition, the Northwest Hall will be reconstructed to provide additional meeting space, so that we will be able to use this space for breakout sessions, rather than be forced to use the smaller rooms in an isolated area on the 4th and 5th floors of the hotel.

○ Some sleeping rooms will be redesigned to allow for an adequate number of accessible rooms with roll-in showers, which equates to one per 100 rooms in the hotel. Current rooms termed accessible will be evaluated and equipped with controls that meet code and are accessible to all.

○ The elevators will be reconfigured to increase the amount of time that doors remain open.

○ All lifts will be self-service and staffed by security to ensure smooth and independent operation.

○ TASH members and staff will provide consultation as renovation plans unfold to ensure that the renovations meet and exceed code to ensure maximum access.

This year in Miami Beach we will be at the Fontainebleau Hilton Hotel and Towers. Our presence at this hotel has already had a demonstrable impact. The site visit earlier this year revealed that the Club Tropigala did not have a wheelchair accessible entrance. At our request, the hotel has already completed construction for an entrance to this popular nightclub. A team of TASH staff and members will be conducting training with hotel staff prior to the conference to ensure excellent service. In addition, we have been working with The City of Miami Beach Barrier-Free Environmental Committee to raise awareness and ensure transportation and beach access for individuals with disabilities.

The rest of society is catching up with what we already know: travelers with disabilities are blazing new trails and, according to the Wall Street Journal, are at the forefront of the next tourism boom. The December 15, 1999 issue of the Journal contained the following headline, "*People with Disabilities Are Next Consumer Niche.*" The article discusses how mainstream companies, from financial services to cell phone makers, are going beyond what is mandated by law and rapidly tailoring products to the disability market. There are currently 54 million Americans with

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Your Conference Revenue Dollars at Work

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disabilities. Of adults with disabilities, 73% are heads of household and 58% own their own homes. The aggregate income of Americans with disabilities is now at $796 billion and will exceed $1 trillion by 2001. In 1995, people with disabilities spent $81.7 billion on travel, not including the expenditures of their family members and other travel companions.

In keeping with our mission, we will take every opportunity and use all measures of leverage to eliminate obstacles, forge new alliances, and promote excellence in and equal access to service.

For those who may be wondering, here are the dates and locations of the TASH Conferences that have been scheduled in upcoming years:

2001 - Anaheim, December 5-8th
2002- Boston, December 10-13th
2003 - Chicago, December 9-11th

Many members have requested that we go back to scheduling conferences earlier in the year again (November), and try to reduce hotel rates. In order to accomplish this in the current booming travel economy, we need to look at sites that are not considered first tier cities. Current cities under consideration are Reno, Orlando, Toronto, Montreal, Minneapolis, Baltimore, Anchorage, and Milwaukee.

If you have feedback about ways we can have impact in the cities we visit, or on site selection, please email me at dmarsh@tash.org or call 410-828-8274 x103.

Don't Miss an Opportunity for Chapter Leaders to Network and Plan for the Future!

In addition to the TASH Techs that are being held on Wednesday, December 6th, TASH is holding the Annual Chapter Leadership Day - An opportunity for chapter officers and representatives to share ideas, concerns and strategies. **There is no charge for this event!**

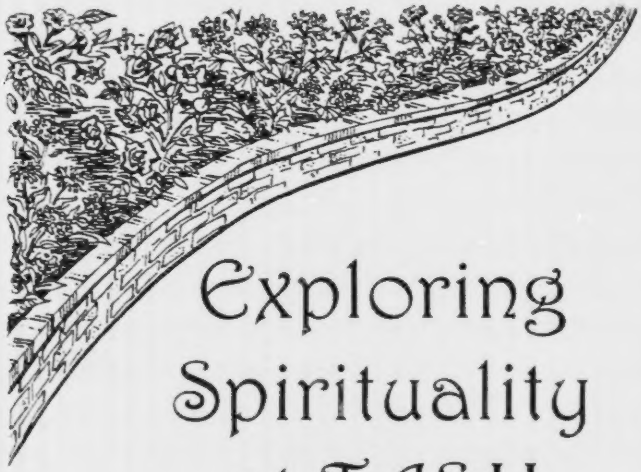
This event has been held on the Wednesday before the conference, in one form or another, for the past five years and has been critical in strengthening relationships between the International TASH Board, Central Office and Chapter Leaders. The day includes opportunities for skill building, informal sharing of ideas and planning for the future. The Chapter Leadership Day has helped new chapters to identify directions for themselves and has assisted established chapters to influence policy and direction within their states. Whether you represent a thriving, a newly established, or a struggling chapter, the 2000 Chapter Leadership Day is an event you won't want to miss!

All current Chapter officers will receive invitations to this exciting day of planning and collaboration. If you are interested in starting a chapter and would like to participate in the 2000 Chapter Leadership Day on December 6th, call Nancy Weiss at 410-828-8274, ext. 101 or e-mail: nweiss@tash.org

Congratulations to the following newly-elected members of the TASH Executive Board!

June Downing
Kathy Gee
Marcie Roth
Dick Sobsey
Lu Zeph

New board members will be installed at the upcoming 2000 TASH Annual Conference in Miami Beach, Florida.



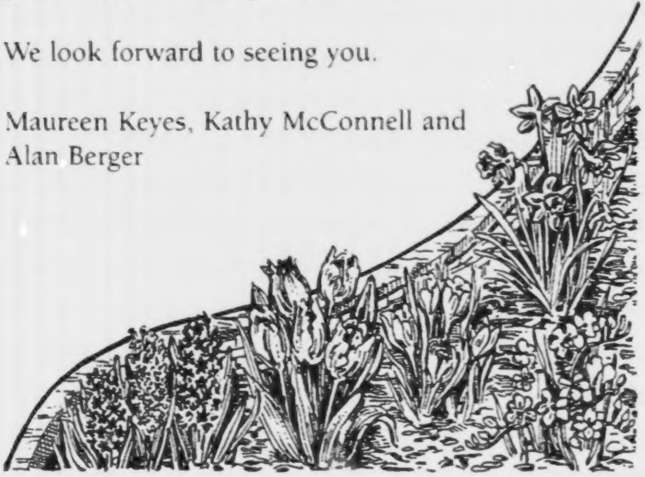
Exploring Spirituality at TASH

Depending on your definition of spirituality, TASH **is** a spiritual experience. For the last two years TASH members and presenters have explored the meaning of "a spiritual life" in relation to our culture and disability. We have covered topics as diverse as access to places of worship, spirituality and person centered planning, and spirituality and leadership.

This year we want to continue the dialogue by having an Open Forum: Exploring the Role of Spirituality in Our Lives (Friday, 12:15-1:15 PM, Le Mans) in addition to individual sessions. We would like anyone interested in exploring this issue to join us. We will also meet separately to discuss the possibility of forming a committee.

We look forward to seeing you.

Maureen Keyes, Kathy McConnell and
Alan Berger



Join others from around the world to network at the

Roundtable Luncheon

ON THE GRAND LAWN

Thursday December 7th from 1:00-2:15 PM.

Enjoy the fresh air and breath-taking view of the pool for lunch while sharing stimulating discussions on a topic that interests you.

Tables will be labeled with suggested topics for discussion, and/or questions to stimulate thought. If you have a specific topic that you would like to discuss during lunch, please fax the following information, or include with your registration form when you send it in the mail.

I would like to participate in a discussion on: ______________________________

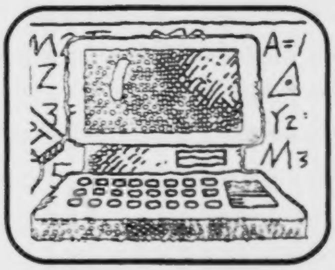
☐ I am willing to facilitate this discussion

☐ I suggest the following person to facilitate this discussion ____________________

Participation in this event is only $10.00, which includes a delicious boxed lunch. Be sure to register when you complete your conference registration form.

Questions? Contact Kelly Nelson at 410-828-8274 x 105 or email knelson@tash.org. You can email your topic suggestions; fax them to 410-828-6706; or send a copy of this ad with your registration form!

Our thanks to Paul H. Brookes Publishing Company for co-sponsoring the roundtable luncheon.



Providing AAC Systems for Children in a Guatemalan Orphanage: How do we help others in culturally responsive ways?

BY JANET M. DUNCAN, Ph.D.

Recent reports of abuse and neglect of individuals with disabilities in the international human rights and disability communities (Rosenthal, 1999), coupled with the recognition that we should provide support to other countries in culturally appropriate ways (Enders, 1999), struck a chord with me in relation to my recent research in Guatemala (Duncan, 2000). I am concerned about communication rights for all as a basic human right (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992.) Specifically, how do we help individuals with disabilities who are living in less than ideal conditions when a framework for understanding disability rights may not exist?

This article focuses on recent research I conducted in a Guatemalan orphanage for children with disabilities. The individuals living in this facility were abandoned by their family, typically at birth or shortly thereafter, and would be considered to have significant disabilities by North American standards. I am concerned about the children who do not have a way of communicating with others in this setting, and I attempted to evaluate their needs and provide them with low-technology augmentative/alternative communication systems (Duncan, 2000.)

This work was accomplished within a larger effort to assist individuals in Antigua, Guatemala through a U.S.-based medical humanitarian mission known as "Faith in Practice." Physicians associated with this group provide free medical care to Mayan villagers at a facility that is used as both a hospital and an orphanage. Individuals with disabilities live in this facility and are grouped by age and disability. The American medical contingent expressed concern about the living conditions of these individuals and invited me to join them to offer any assistance. Not knowing what I would discover, I agreed to visit Antigua.

My concern at the outset of this action research project focused on providing low cost AAC systems in a culturally responsive way (Enders, 1999.) The example of being asked for technological assistance provided by Enders (1999) in the article, *"What is culturally appropriate? Finding a middle way,"* (TASH *Newsletter*, October 1999) describes the circumstance in which I found myself. I did not want to impose my expectations on others without understanding the social context of this setting. As a North American with a general interest in disability rights and a specific interest in communication rights for individuals with significant disabilities, I was eager to learn more about the needs of these residents.

As a qualitative researcher I also wanted to learn about the perspectives of the individuals who live and work in this facility (Bogdan & Biklen, 1992). Specific questions I had in mind were:

○ how do residents of this facility see themselves?;
○ how do workers see the residents?;
○ what are the ways in which residents communicate?; and,
○ how is disability viewed in this particular facet of Guatemalan culture?

Understanding the nature of the setting and the perspectives of the individuals in this setting was a major focus.

This research perspective fits with an action research model enabling a researcher to study situations while simultaneously providing support through everyday practice (Meyer, Park, Grenot-Scheyer, Schwartz & Harry, 1998.)

While these questions were at the forefront of my research agenda, I also wanted to provide children with the immediate benefit of AAC technology and support. There were communication systems that I could provide on the spot, enabling individuals to communicate with others (Duncan, 2000). Simple letter boards constructed from paper with letters and pictures were made within minutes.

> We need a coherent set of strategies aimed at helping individuals in specific settings and offering assistance to communities and governments. At the same time, we must respect different cultural understandings of disability, education and human rights.

The limitations of this preliminary study are significant. The largest hurdle I faced was working through a translator to speak with workers and children in the orphanage. Nevertheless, I found people were eager to talk to me and expressed interest in my work. I was definitely not seen as an insider, though and it would take considerable effort and time to be fully accepted in this setting.

Another factor was the limited amount of time I spent in the setting (two weeks.) The residents and workers were used to the American medical personnel coming and going, and viewed me as part of the rotating team of professionals who would likely be coming back

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Providing AAC Systems for Children in a Guatemalan Orphanage

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someday. Indeed, many of the Faith in Practice workers return annually, with more frequent visits for some. I intend to return as well to continue this study. In spite of the limitations of my work, I was able to assess several children and offer them low-tech AAC communication systems (Duncan, 2000.)

Several compelling issues remain for me as I think about our efforts to assist others internationally. Specifically, how do we support individuals with a sensitivity to other cultures? In the Guatemalan case, I need to understand the situation in terms of the recent civil war with a deep respect for family losses, separations, and a basic distrust of anything related to the government. Religion plays an important role in this society, with the predominant view that individuals with disabilities are, "children of God." The individuals in this setting are housed in a religious affiliated institution that is believed to provide sanctuary for the residents and workers. It is a "House of God." They did not view the facility as an institution, with all that means in our North American context. Yet, I viewed the setting as such. The bougainvilla-filled courtyards and verandas, while beautiful, were analagous to our notion of a "day room." The workers still line up all the children in rows on the floor and bird-fed them similar to the conditions at St. Nicholas described by Rosemary Crossley and Anne MacDonald (1984.)

Children were not educated in a formal sense as we would expect institutions to provide a basic level of education to residents. Very few decorations, toys, or educational materials were available. Yet workers sang to the children, spoke lovingly to them, and related to me that they were doing "God's work" by caring for them. Other examples of caring include special hair adornments for the female residents and home-cooked treats for all to share. Many of the children were referred to with terms of endearment by the workers.

While the workers may love the children, basic medical care was extremely limited. Workers expected many of the children to die. A special room designated for malnourished children was established for the ones who failed to thrive. It seemed to me that the primary reason for their failure to thrive was the inability to feed the children due to their contorted bodies and lack of positioning techniques. No physical therapy sessions or equipment were provided. A few standard wheelchairs donated through the medical group were shared among all the residents.

When I asked workers about the activities of the older residents, they described vocational opportunities within the facility for those who were physically capable of working. Examples of work included washing and polishing the tile floors, cleaning the bathroom facilities and "wards", assisting with personal care of other residents, and kitchen and laundry duties. The workers explained that residents would be trained one-on-one until the job was performed satisfactorily. This training seemed analagous to vocational training with natural supports and job coaching models common in our communities. All of the work was performed inside, however, with no opportunity for residents to leave the facility. When questioned about this workers responded, "Why would anyone want to leave God's house? It is safer here." Again, in the context of a community with civil war in recent memory, it seemed understandable to me.

My work in Guatemala has just begun and the research questions are mounting. I welcome any dialogue with individuals who have similar interests and who wish to develop models of advocacy for individuals worldwide.

A question about community living arises, too. How would we suggest options for community living in this context? Finding original communities and family members may be difficult. The administrator of the facility told me that family members brought their loved ones to this facility in the hope that they would be safe and cared for, much like the hopes of family members in our earlier days of institutionalization. Living in this facility is viewed as a privilege. How would we describe the benefits of returning to war-torn, impoverished communities? Many Mayan villagers do not own land and exist purely on a subsistence farming basis through squatters' rights. Able-bodied children are put to work as soon as possible to provide an income for the family.

Recently others have described shocking living conditions of facilities in other countries (Rosenthal,1999.) This is a grave concern for TASH members as we struggle to advocate for people with disabilities worldwide. The efforts of organizations such as Mental Disability Rights International (MDRI) and Amnesty International should be a major focus for TASH. It is of particular concern when countries seek to build new facilities in an effort to be "modern" and supportive of people with disabili-

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ties. There is a growing need for balancing the interests of governments in their attempt to modernize care for citizens with disabilities, and our North American view of providing supports for individuals in a culturally responsive way.

We need a coherent set of strategies aimed at helping individuals in specific settings and offering assistance to communities and governments. At the same time, we must respect different cultural understandings of disability, education, and human rights. We must not lose sight of our mission to educate others about the rights of individuals with disabilities within the context of culturally appropriate practices. A combination of culturally appropriate efforts advocated by Enders (1999) in concert with an organization such as Mental Disability Rights International (MDRI) is an urgent need.

My work in Guatemala has just begun and the research questions are mounting. I welcome any dialogue with individuals who have similar interests and who wish to develop models of advocacy for individuals worldwide.

Juan Carlos, the 20-pound, ten year old boy with cerebral palsy may have a few years of meaningful conversations with his new communication board. He was the first child with whom I worked simply because in the large room with fifty cribs he was the one who screeched loudest to get my attention. Undoubtedly he is a freedom-fighter waiting for his chance to speak.

For further information, please contact Janet Duncan, Ph.D., Assistant Professor in the Education Department at Le Moyne College, Syracuse, NY 13214-1399. Dr. Duncan may also be reached by e-mail at <duncanjm@maple.lemoyne.edu>, or by telephone at (315)-445-4796.

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SEEC

Position Vacancies

Special Needs Support Staff (Part-time)
Opportunity to assist young lady with developmental disabilities in Middletown area with recreational activities.

Ten to fifteen hours per week. Flexible schedule. High school diploma required and prior experience with developmental disabilities preferred. Salary commensurate with experience.

LPN/CNA (Brunswick, Maryland; Part-time)
Work with young lady with developmental disabilities. Administer medications, write and monitor plan of care, nursing interventions and monitor condition of patient. Salary commensurate with experience.

Send cover letter and resume to:

SEEC
Human Resources
707 Conservation Lane
Suite 200
Gaithersburg, Maryland 20878
Fax: (301) 527-0119
E-mail: SEECHR@aol.com

EoE/M/F/V/D

Me & My Assistive Technology: High School Students Write About their Assistive Technology

BY HANK BERSANI

Making the transition from high school to life as a young adult is a difficult task for most teens. Add in the factors of disability and assistive technology (A.T.), and transition becomes much more complicated. For the last 5 years, longtime TASH member Hank Bersani has been working with teens who use a variety of assistive technologies and their transition teams to help smooth the transition process. As a part of that process, Hank and his colleagues, Tina Anctil and Melanie Fried-Oken, have assisted teens to write about their personal experiences using A.T. in high school and as young adults.

These two essays were produced as a part of Project TechTrans, a U.S. Department of Education-funded project focusing on issues in high school transition for teens who use assistive technology.

These essays, and several others all written by teens who use assistive technology, were recently published in a booklet titled Me and My A.T.

The booklet is designed to be used in high school transition programs, and of interest to students and families since it is written entirely by students.

Me and My A.T. is the latest publication by Bersani, who has spent the last several years assisting authors with disabilities to find their voice and publish their insights. Hank Bersani may be reached via e-mail at <Hankbersani@aol.com>

Me and My A.T. will be available in December from the publisher, Northwest Media Inc., Eugene, Oregon, <www.northwestmedia. com>

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FREEDOM

BY MATT BOYER

Freedom. That's what assistive technology means to me. My first "assistive devices" were my parents. My mother read to me for hours on end. I puffed along with *The Little Engine That Could*, pulled the lever of my toy dump truck when *The Happy Man and His Dump Truck* took his friends for a ride, and giggled during lunch to *Green Eggs and Ham*. My Dad was my hands and feet. He'd hold me tight as he ran down the street in the wind and rain. He'd pour sand into my hands and laugh with me as it flowed between my fingers.

Music was a part of every day. Squeakers, cymbals, keyboards, little plastic tooters, and glasses filled with varying amounts of water pleased me. Well, not the squeakers. The first memory I have is that of a loud, scary noise blasting in my ear as I played my favorite game of banging my head on the floor when I was about 18 months old. My folks tell me that no amount of distraction could stop me from banging. I liked it. Finally, my mother slipped a soft squeaker toy under my head as I began to drop it for a really good bang. SQUEAK! I was cured.

My parents pushed the buttons on the tape player until grew I strong enough to do it myself. The day I voiced over a number of my brother's cassettes was the day all of the general family cassettes mysteriously disappeared. They didn't return until I could be trusted not to put motor sounds or sing-alongs in the middle of a story.

Bob, a speech pathologist, was another help to me. At one time he concluded that I should use a device in my mouth to help me with the sounds of 'p' and 'b'. I didn't like what I understood of that idea, so we didn't do it. We were both very surprised and happy when sometime later I could suddenly 'pa' and 'ba' with the best of them. A braille access keyboard (Braille-'N-Speak) soon served as an augmentative communication device. A Multi-Voice was added later for clarity of speech.

When I was eight, the Make-A-Wish Foundation purchased a Braille-'N-Speak, an Apple IIGS with voice output, a printer and a braille embosser for me. WOW! The easy to push buttons of the Braille-'N-Speak decreased my fatigue in writing when compared to using an electric brailler (similar to a typewriter) and an abacus. School work became easier and the portability of the Braille-'N'-Speak has been a lifesaver during the months each year I've spent in bed either in the hospital or at home.

My current arsenal of tricks includes a Braille-'N-Speak Classic (which is an electronic talking braille note taker with a built-in calculator, clock, calendar, stopwatch, and countdown timer) a BNS 640 (similar to a BNS classic with more room to take notes), a MultiVoice (a device that takes the output of what I write on the BNS [either one] and speaks it in a more intelligible voice), an IBM-

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Me & My Assistive Technology

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compatible computer with a variety of speech output programs, screenreaders, (Jaws For Windows and Jaws For DOS), optical character recognition program (Ruby), and braille translator (Duxbury Braille Translator), a TSI braille embosser, a Hewlett Packard Laser printer, a Franklin Language Master (a portable talking dictionary with ten word games), and a Hewlett Packard 5200 scanner that reads print.

I use the Braille-'N-Speak to keep a diary (called "Night Life"), do my math more easily, keep an appointment calendar, keep track of names and e-mail addresses, write some of my programs on, and to keep a log of what we're doing on trips. I use the MultiVoice to communicate with people who don't understand my speech or the Braille-'N-Speak's speech.

For a number of years I have slept in an electric bed with the head elevated so that I can breathe more easily when I am asleep. Having the head elevated is also helpful when I'm too tired to sit up to read. I can just rest back and cruise along.

I've used wheelchairs since outgrowing my parents' arms. My favorite one is gathering dust in the garage. It's an electric scooter that can go faster than my parents can run. The combination of being blind, liking speed and vehicular traffic is not safe they tell me. The scooter will remain in the garage until I figure out a way to know where I am quickly enough to navigate without threat to myself or my mother's vocal cords.

I'm home schooled, which has worked well. My folks, never shy about going places or doing things, brought the world to me when all I could do was think and breathe. I did go to public school kindergarten but it wasn't the best for me. The ambient noise made hearing the teacher hard. My clearest memories of kindergarten are the following:

Memory #1: Hearing my personal attendant tell me to imagine the shape of 'I' as the teacher wrote it on the board way up in the front of the room. It's good that I knew the shapes of both print and braille letters BEFORE I went to kindergarten because I never could have imagined an 'I' if I had never seen one before that day.

Memory #2: Coming home with an itchy head and having my mother drag me off to the doctor for a nonpoisonous means of solving the problem. I thought the itch and the little bugs I couldn't feel was pretty cool though, and complained about the cure.

Memory #3: Finally there were the wonderful choking noises my mother made the day she found a list of all the new words I'd heard at school. First she told me I was a great phonetic speller. She then corrected my spelling and supplied the definitions. I've not used those words since, but I've often wondered what I could do to get mom to make those noises again.

"Having the right tools, however, adds to my will to participate in my own life. As the Blazie Engineering song goes, 'Technology, technology. It's my key to being free.'"

I'm a high school senior now, planning a career in computer programming. My early and continued exposure to tape players, computers, augmentative communication devices, and other gadgets that scan print or speak have encouraged me to try to learn how to improve the quality of sound programs. I plan to finish high school and then I'll begin college courses through the computer because I'm slow moving and traveling makes the days too long sometimes.

I try to stay in touch with the newest in computer use and programming by having someone read books or magazines to me and by listening to tapes, manuals on disk, and radio programs. I took a class in Programming in C through the Oregon Graduate Institute's Saturday Academy in 1996. The 60 mile drive and the immense hassle in trying -- and failing -- to completely adapt my equipment to that in the school room was discouraging. I never would have made it if either my brother, my father or my mother had not been there to read the screen to me. I did stick it out, though. I did my own work and passed the class. I had to laugh at my mother: she'd read the screen to me and then ask in a very puzzled whisper, "What did I just say?"

My parents have always encouraged me to make my own decisions. Sometimes, though, it is easier to just have someone else think, speak or do for me, but I try to fight the laziness that fatigue and pain bring. I talk with my family and friends about ideas, do research and pray in order to find the right thing to do.

It's difficult dealing with those "outside'"my circle (strangers, people in a hurry, doctors, etc.) because the reality of my blindness, slurred speech, weakness, and my need for frequent medication seems to make people nervous and they act as if I cannot think properly. It's odd, too, how some people seem to yell at me. It's as if they think that since I am blind, I must obviously be deaf, too. Maybe they are just trying to shout down the wall they believe is between us. I don't know.

Having the right tools, however, adds to my will to participate in my own life. As the Blazie Engineering song goes, "Technology, technology. It's my key to being free."

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Me & My Assistive Technology

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LIFE IS GOOD

BY CLAUDIA PANIAGUA

Of the things I have learned, I learned that life is good! That no matter what the circumstances are, no matter if you are rich or poor, tall or small, kind or bad, able or disabled; life is a gift, a perfect gift. We have been given everything to be happy. It is up to us to decide if we want to enjoy it or not.

I have chosen to enjoy life because I have realize that I have everything to be happy about. My family and my friends, whose love for me has been there when I most needed them. When I was fragile, my bones failed me. When I broke in desperation and cried, when I was ready to surrender because of the pain, when I felt lonely and incapable, and when I felt "disabled," they were there, beside my bed, comforting me. My family is one of the many wonderful gifts God has given me. I believe with all my heart that God is the strength that has helped me throughout my life.

And with that, I want to introduce myself to you. My name is Claudia Paniagua. I was born and raised in El Salvador. At birth I was diagnosed with Osteogenesis Imperfecta (brittle bones). I am unable to walk, so I use two wheelchairs (one at a time!). When I am at home, I use my manual chair to move around, and out in the community I use my power chair (my little corvette).

I came to America when I was 16, and I've been here for about six years. When I came I did not speak any English whatsoever, and it took me two years to feel comfortable with my new language.

I graduated from high school in 1997. I am now attending Western Business College. I am twenty-one years old and planning to get my certificate as a Computer Systems Operational Specialist by the end of this year. So far so good. I already finished my first mini-term of six weeks! After graduation I plan to work full time. I would like to have a job with the government.

I'm about 3 feet tall and weigh about 60 pounds. Because of the severity of my disability (my bones break easily), I am unable to walk. So I use an assistive technology device, which is a power chair. This chair is not like you might think of a wheelchair. It has a neat feature which allows me to go up to five feet high and all the way down to the floor. It's a great help because now I can reach for things that are up on a counter, and I can reach for things that I drop on the floor. I can also look people in the eye.

I want to share with you how my assistive technology device has help me. I am very happy with my life right now. Everything seems to go the way it should go. It wasn't always like that. Six years ago, I did not know what was going to happen with me. Everything seemed so blurry. When I first moved to America, I started going to high school. I was using a manual wheelchair, but it was difficult to use at school because the high school that I attended was very large and the classrooms were far apart from each other. Most of the time my classmates helped me get to class, but it wasn't fair to them because they were always late for their own classes. They were nice and did it, anyway.

I met a lot of nice people at school and among them was my therapist. He recognized the problem I was having and he knew I would need another assistive technology device other than the one I was using.

He started talking to me about the possibility of getting a power chair. I remember loving the idea. The only problem was that I did not have the resources to get it. One day we were looking at a powerchairs catalog that a salesperson showed us, and we saw this "wonderful chair that would fit my needs." The only problem was that we did not have the resources (money) to get it. It was expensive!

After talking to many people about my problem in getting the chair that I needed, it was suggested that we apply to the International Rotary Club of Tigard, Oregon. They were willing to put some money into this project. We also found another organization, Wheels of Power, which helps people with a disability to get around and to be independent, and they also helped us. Disabilities Services also played a great part in fulfilling this dream of mine. This is how we arranged for the money to buy the chair I needed. And now this chair is part of my daily life when I go to school, and I know it is going to help me when I go to work.

When I got out of high school I worked in a bank as a loan processor. I enjoyed working there, but it was a temporary job. When the position ended, I wanted to find another job and there were people to help me find one. A youth transitional program worker was one of the people who helped me. She gave me advice on what to look for. But the time passed and I couldn't find a job because I did not have much schooling, so I realized that I needed more studies. And that is the reason why I decided to get back to school. I needed to get more skills to go to work and offer my employers something else than just a high school diploma. Computers have also been my enthusiasm and I thought this was the time to go into this career, now that I have the opportunity. I got the blessing of my family who is there to encourage me to do so. As I said before, after school I want to find a job with the government. I know it is not easy, but it is not impossible, either.

In conclusion, I know I can do all things through God who strengthens me and with the right people to help me. All of us people with disabilities are able to do what we want with a little willingness and a little persistence, not quitting at the first obstacle, but keep on going until the goal has been reached.

Do not quit - persist. The star of success is waiting.

TASH and Others Meet with President Clinton

Continued from page 4

the institutional bias of federal long-term care policy. "Ask the next thirty people you meet today what their goals are for their golden years," I urged the President. "Not one of them will say, 'to end up in a really nice nursing home.' Living in a nursing home or any other type of institution isn't what anyone would choose for him or herself or for a loved one." "So how," I asked Clinton, "did we end up with a system that provides only one choice - and it is a choice that no one would choose?" This line of thinking seemed to resonate with the President. Clinton asked me if I personally knew of families who had been forced to place their child in an institution for lack of medical insurance. I assured him that I did and that institutionalizing a child isn't a choice any family would make if given reasonable options for home supports.

The President assured participants that he would urge the Congress to pass the bipartisan Grassley-Kennedy-Sessions-Waxman Family Opportunity Act of 2000 (S. 2274 and HR 4825). This bill invests $2.1 billion over five years to establish the Medicaid buy-in option.

Both Mike Auberger and Mike Oxford talked about progress that had been made in Colorado and Kansas in getting folks out of nursing homes and Auberger emphasized the cost effectiveness of community-based care. Auburger and Marchand also talked about the importance of expanding access to housing vouchers so people can afford to live in the community. The President noted that he had just negotiated funding for 79,000 new housing vouchers and he would look into whether some could be earmarked specifically for people with disabilities.

Bobby Silverstein talked about some emerging issues in implementation of the Work Incentives bill, and emphasized the need for inter-agency collaboration to break down the ongoing barriers that are making potential participants reluctant to take on jobs and risk benefits. Clinton assured the group that as part of the current budget negotiations, he would urge Congress to finish the job on the Work Incentives Improvement Act by providing permanent Medicare coverage to people with disabilities returning to work.

Barbara Toomer asked for an assurance that the new Medicaid eligibility proposed rule that the President had just announced that morning would go into effect before the President leaves office. Clinton and Chris Jennings assured her that it would. James Billy talked about the importance of enforcement and compliance with existing laws and the need for more accessible, affordable housing. Andy Imparato emphasized the civil rights enforcement budget and Paul Marchand reminded the President of the 25th anniversary of IDEA next month and encouraged the President to organize an event elevating the importance of the anniversary as he did for the 10th anniversary of the ADA. The President promised that he would organize some kind of event recognizing the anniversary of IDEA.

The meeting lasted about 45 minutes. The President showed real interest in the concerns raised by the advocates, took notes, asked questions, and instructed staff to follow up on specific issues.

Special thanks are due to the hundreds of ADAPT activists, Mary Beth Cahill, John Podesta and Jonathan Young for making this meeting possible.

Thanks to Andy Imparato and the NHOYO list serve for their contributions to this article.

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MENTAL HEALTH, MENTAL RETARDATION AND PROTECTION OF RIGHTS UNDER INTERNATIONAL LAW

Excerpted from a report by Mental Disability Rights International

Research and publication of this report was primarily funded by the Public Welfare Foundation and the John Merck Fund.

International Human Rights Law

For many years, the promises of international law have not been fulfilled for people with mental disabilities (mental retardation and mental illness). The Universal Declaration of Human Rights (UDHR) of 1948, the foundation of international human rights law, declares that "[a]ll human beings are born free and equal in dignity and rights. They are endowed with reason and conscience...." The UDHR protects against discrimination on the basis of sex, race, religion or "other status." In theory, people with disabilities have always been protected against discrimination by the UDHR, but it took many years before the international community began to examine the application of this right to people with mental disabilities. While proper enforcement has historically been lacking, core human rights law that applies to all people do—as a matter of law—provide the same rights to people with mental disabilities.

Over the last few decades, the United Nations General Assembly has adopted a series of resolutions that can serve as a guide to the application of human rights law for people with mental and physical disabilities.[1] In 1971, the United Nations adopted the Declaration on the Rights of Mentally Retarded Persons[2] (the MR Declaration) and in 1975 adopted the Declaration on the Rights of Disabled Persons.[3] Despite the universal application of these human rights, the international community for many years neglected to hold states accountable for the enforcement of these rights with regard to people in psychiatric institutions.

In 1982, the United Nations brought international attention to the concerns of people with disabilities by declaring the "Decade for Disabled Persons," leading to the "World Programme of Action Concerning Disabled Persons."[4] As part of the Decade for Disabled Persons, an international team of experts began working on the development of international human rights standards that would set forth the obligations of all governments for people with psychiatric disabilities.

As the United Nations was drafting human rights standards for people with mental illness, regional bodies in Latin America, such as the Pan American Health Organization (PAHO) took the lead in calling for nations to take concrete steps to ensure the protection of human rights for people with mental disabilities.[5] In a historic meeting convened by the Pan American Health Organization in November 1990, the Declaration of Caracas was adopted by legislators, mental health professionals, human rights leaders, and disability rights activists from North and South America. The Declaration of Caracas represents consensus among professionals and others in the Americas that exclusive reliance on the psychiatric hospital "isolates patients from their natural environment . . . generating greater social disability."[6] The Declaration concludes that such conditions "imperil the human and civil rights of patients."[7]

The Declaration of Caracas calls on national authorities and nongovernmental organizations (NGOs) to restructure mental health care systems to "promote alternative service models that are community-based and integrated into social and health care networks."[8] Mental health resources must be used to "safeguard personal dignity and human and civil rights"[9] and "national legislation must be redrafted if necessary. . ."[10] to ensure the protection of human rights.

The principles underlying the Declaration of Caracas received a major boost in 1991 when the United Nations General Assembly adopted the Principles for the Protection of Persons with Mental illness and the Improvement of Mental Health Care (the MI Principles).[11] The MI Principles are the product of a decade-long effort by experts from around the world to set forth minimum human rights standards for people with mental

Today in the Americas, Europe, and other parts of the world, many countries have adopted laws against discrimination on the basis of mental disability. These laws help people obtain employment, housing, and access to public services. These laws have been an important part of the process of mental health reform and have greatly helped people with mental disabilities to live full lives in the community.

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MENTAL HEALTH, MENTAL RETARDATION AND PROTECTION OF RIGHTS UNDER INTERNATIONAL LAW

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disabilities. In the absence of a specialized convention on the rights of people with mental disabilities, the Inter-American Commission of Human Rights has held that MI Principles can serve as an authoritative guide to the interpretation of the mental health law, as it applies to people with mental disabilities.[12] The MI Principles are also a useful tool for international human rights documentation, because they provide a fair and consistent standard for the evaluation of human rights practices in mental health systems around the world.

The MI Principles apply broadly both to people with mental illness, whether or not they are in psychiatric facilities, and to "all persons who are admitted to a mental health facility,"[13] whether or not they are diagnosed as having mental illness. The MI Principles protect all such people against discrimination,[14] and they detail a list of rights intended to ensure that people detained in mental health facilities are "treated with humanity and respect for the inherent dignity of the human person."[15]

The MI Principles have major implications for the structure of mental health systems, as they establish that "[e]very person with a mental illness shall have the right to live and work, as far as possible, in the community."[16]

Within Europe, the World Health Organization (WHO) has found "a remarkable degree of common ground" regarding the importance of shifting away from reliance on large psychiatric institutions and promoting community-based services that permit the maximum possible integration into the community.[17]

The MI Principles specify that people receiving mental health treatment have the right to protection against "harm, including unjustified medication. . . ."[18] Treatment must be provided "based on an individually prescribed plan . . . "[19] The MI Principles also ensure that "[n]o treatment shall be given to a patient without his or her informed consent . . . " except under special circumstances set forth in the MI Principles.[20]

Today in the Americas, Europe, and other parts of the world, many countries have adopted laws against discrimination on the basis of mental disability. These laws help people obtain employment, housing, and access to public services. These laws have been an important part of the process of mental health reform and have greatly helped people with mental disabilities to live full lives in the community.

The full report, Human Rights & Mental Health: Mexico, by Mental Disability Rights International (MDRI), may be ordered from MDRI at 1156 15th Street, N.W., Suite 1001, Washington, D.C. 20005; Telephone: (202) 296-0800; Fax: (202) 728-3053; E-mail: MDRI@MDRI.org; Web page: www.mdri.org

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[2] G.A. Res. 2856, U.N. GAOR, 26th Sess., Supp. No.29, at 99, UN Doc.A/8429 (1971).

[3] G.A. Res. 3447, U.N. GAOR, 30th Sess., Supp. No.34, at 92, UN Doc. A/10,034 (1975).

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[5] *See* Itzhak Levav, Helena Restrepo and Carlyl Guerra de Macedo, *The Restructuring of Psychiatric Care in Latin America: A New Policy for Mental Health Services*, 15 J. PUB. HEALTH AND POLICY 71 (1994) (describing developments in mental health, policy, and law underlying the Declaration of Caracas).

[6] *Id.* at 83, *preamble*, paragraph 2.

[7] *Id.*

[8] *Id.*, article 1.

[9] *Id.*, article 3.

[10] *Id.*, article 4.

[11] G.A. Res. 119, U.N. GAOR, 46th Sess., Supp. No.49, Annex, at 188-92, U.N. Doc. A/46/49 (1991). *See* Rosenthal & Rubenstein, *supra* note 11 (analyzing the protections of the MI Principles and describing their use as a guide to the interpretation of human rights conventions).

[12] Case of Victor Rosario Congo, Report 29/99, Case 11.427, Ecuador, adopted by the Commission in Sess. 1424, OEA/ser. L/7.102, doc. 36 (1999). The Inter-American Commission cited Rosenthal and Rubenstein, *supra* note 11, for the proposition that the MI Principles can be used as a guide to the interpretation of human rights covenants. Case of Victor Rosario Congo at 8, n.7.

[13] MI Principles, principle 24.

[14] *Id.*, principle 1(4).

[15] *Id.*, principle 1(2).

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[20] *Id.*, principle 11(1).

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CORRECTION: The article, *Individuals with Significant Disabilities and Consent to Sexual Activity*, (TASH Newsletter, May 2000) was incorrectly identified as having been written by James K. McAfee and Pamela Wolfe. Dr. McAfee was the sole author of the article. Our apologies to Drs. McAfee and Wolfe.

New Voices in Iceland:

Growing up with a disability

BY DORA S. BJARNASON

"How do you grow up if you have a disability?"

In 1998 I became involved in a research project with young adults with disabilities, their parents, friends and teachers. The study, which is still in progress, tries to understand the world of young people with disabilities in Iceland, the first generation to grow up with the ideology of integration and inclusion as the law of the land.

We are first interested in situations and experiences of individuals who have disabilities that lead to social discrimination; how they see themselves and how they are perceived by parents, friends and teachers. Second, we want to learn what young people with very different disabilities have in common, what is different in how they experience their situation, and how that may be related to different social situations and decisions made by their parents and teachers because of their adolescence rather than their disability.

Iceland - A Small Nordic Welfare State

Iceland is a volcanic island approximately the size of Ireland, on the North Atlantic ridge between Europe and America. Its population is small, a little over a quarter of a million. The Icelanders are still remarkably homogeneous, largely descendants of Nordic and Irish people who populated the country in the 8th and 9th centuries. Today Iceland is a modern society where people in general enjoy a high standard of living and good education.

For a millennium the Icelanders were largely subsistence sheep farmers, living on isolated farms scattered around the coast. For centuries the island was a Danish colony with no towns or villages. Most people were either subsistence farmers, servants or paupers. Life was hard due to natural calamities and epidemics. Throughout Icelandic history, the family by law had to look after its own, but if a person had no family, the law obliged the Church and the community to take care of people in need.

Thus the poor, the sick, the elderly and those with disabilities were placed from one year to the next with farmers, for a fee. The industrial revolution took hold of Iceland at the beginning of the 20th century, resulting in its rapid transformation into a sovereign, democratic, Nordic-type welfare state.

Currently, almost two thirds of the population live in and around the capital city Reykjavík and Akureyri in the north, while the remaining population lives either in tiny fishing villages or on small farms. The laws about the welfare system are similar to those in other Nordic countries, but there is less of the taxpayers' money to cover welfare policies. The state provides pensions for the elderly, unemployed, sick and the disabled. The money does not suffice, so in case of hardship if people have no other source of income, the local communities supplement these pensions. The state also provides free education from the age of 6 to 16 and a largely free education at tertiary and university levels, free or low price health services, rehabilitation, medicine, and technical aids for the elderly and people with disabilities.

> *Although the study is not yet complete, we have seen that the level and type of disability label has less impact upon the quality of life for these young adults -- such as their friendships, activities, and their belief in their ability to become adults -- than parental support and expectations, schooling, and supportive, nurturing non-family relationships.*

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Normalization and social integration became the law for people with mental retardation in 1979. In 1983 the law was changed to embrace all people with disabilities except people with chronic mental illness, who were finally included under the law in 1992.

The Icelandic value base is ruggedly individualistic and egalitarian. There is a long tradition of working and helping one's self, and a commitment to the principle of mutual help to those in hardship situations. For almost a century the community has been obliged to take care of people in need. In modern Iceland, as in almost every other country, some are more equal than others. Differences in wealth and status are growing, marginalization of minority groups is a known phenomena, and people with disabilities tend to be rather less than equal than most according to any measurement one might select.

The Study

The study looked at young Icelanders (16-24 years old)[1] with disabilities, people from urban and rural sectors, from different socio-economic backgrounds, and people with a broad range of disability labels. Young people with disabilities in Iceland have not been the focus of scholarly endeavor, and there is little information available about the social forces that influence their lives.

The purpose of the research that we have embarked upon is to explore how young adults with disabilities experience their lives and possibilities at school, work and in society. We are interested in learning to what extent their activities, feelings and hopes are related to their disability, social situation, origin, family type and support, friendships, the way in which their teaching and learning is organized, and the kind of support they receive at school. We base our approach on the notion that reality is always a process of social construction. Thus by letting people tell their stories, we try to understand how they act in response to the "meanings" that their situations have for them.

Personally, I bring a number of perspectives to this research. Not only have I been doing research on integration and later inclusion and inclusive practices for the past ten years, I have also been trying to learn more about how to prepare educators, student teachers and developmental therapists to work in inclusive schools and other public settings. Finally, I am a parent of a 20 year old son who has significant disabilities (physical, sensory and cognitive). This shapes and molds my questions concerning the subject under discussion.

This is a qualitative study and the main method of collecting data has been indepth interviews. Over the past two years I have interviewed 36 young adults with a variety of significant disabilities, one or both parents or support persons of 32 young adults, 12 teachers, and 12 friends. The interviews were indepth, semi-structured and lasted from 45 minutes to over 2 hours.

A young woman of 20, who has spina bifida, helped me with the interviews with the young adults. She was my assistant, but also my guide into the habitat of young people with disabilities, and my interpreter as she helped me to understand both slang and slurred speech.

I brought two broad questions to this study. First, what do these young adults, their parents, teachers and friends, believe hinders them most in pursuing their learning, working or participating in society as adults, and what is most helpful? Second, what are the young adults' hopes and expectations for their future as adult members of society? Three no less broad questions have emerged from the data. These are:

1. What does it mean to be an adult with disabilities in Iceland?

2. How do young people see themselves reach adulthood when they have significant (multiple) disabilities, and how do they negotiate adult status?

3. To what extent is this related to age, biological and physical situations, and to what extent has this to do with type of parenting, social status and bureaucracy in Iceland?

Some of the study's preliminary findings were very enlightening. For example, all of the young people interviewed (except for one young woman who did not expect to live very long and said that she had "swept all her dreams under the carpet") harbored similar dreams. They dreamed of becoming independent of parental authority, living in their own homes, working, having friends and sweethearts. Many hoped eventually to get married or find a permanent partner. Just over half of the young people admitted to a dream of having children of their own, but some of those said that they could not realize that dream because they had been sterilized. A few were very bitter about this, while others explained this as an unavoidable necessity "because my mother does not want to help" as one young man in a wheelchair said. "She does not want to get stuck with my baby and I cannot look after it on my own," said a young woman with very bad eyesight and an intellectual disability.

Not one of the young people dreamed of living in a group home in the future, but many saw themselves in a sheltered workshop despite the dismal pay. Three young people were already living in group homes, but hoped they would be able to move to a home of their own. Some of the young people seemed pretty certain that they could fulfill their dreams, but later than their non-disabled age peers, others seemed much less certain. One young woman of 20 put it this way "this is my dream if I am allowed to grow up some day."

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In the fieldwork we were struck by the difficulties some of the young people had to overcome to be accepted and to accept themselves as adults.[2] Further, it soon became clear that these difficulties had less to do with disability labels than a number of other factors, such as where the person went to school, whether the person had friends that did not have disabilities, as well as friends that did, and the nature of their parenting and parental support.

If they knew that they had at least one parent, or parent figure, who expected much and supported them in their hopes and dreams, it was easier for them to believe that they might become "fully adult" in society. The exception to this was two young adults with autism, where the disability seemed to be the most influential factor in their lives. For the rest, their schooling, expectations of teachers, the way parents dealt with them and their disability, and their friendships seemed key determinants in their perceptions of themselves and their ability to fulfill their dreams for adulthood.

Two themes emerged from the data, on how one reaches adulthood. The first refers to adulthood that comes slowly but surely, and the second that one will become adult biologically and bureaucratically but not necessarily socially. Regarding the first theme, young people felt that they had to earn adulthood by extremely hard work and diligence. They thought that by working harder at school or at work than anybody else, that they would eventually graduate or be promoted and do well. That eventually might get them most rights and privileges of adulthood. This was reflected by young people with a variety of disability labels ranging from physical, mental and sensory disabilities to mental illness. Another version of this theme was that some felt that they would have to fight for their adulthood every inch of the way, but that they would eventually get there.

The second theme, the belief that the young people might become adult in the biological and bureaucratic sense but not necessarily reach adulthood in the social sense (or if at all, then it would be far into the future), was held by a disproportionate number of young people with intellectual disabilities, but also by a sizable number of young people with a variety of physical and sensory disabilities. The young people who found it hard to see themselves becoming fully adult felt that they had serious needs and not enough supports to secure the social status of adulthood. Three young people, two of whom knew that they were dying, and a young man who had been very significantly disabled through assault did not expect to become full-fledged adults in the social sense.

In this study we have traced how social processes that are set almost as soon as there is a diagnosis of disability shape the lives of young adults with disabilities and impact their future prospects of reaching their dreams for full adulthood with all of its duties, rights and opportunities.

This is important in two ways: at a theoretical level, it adds to our understanding of the process of how society "handicaps" people with disabilities. At a more practical and pragmatic level, it can suggest better and more powerful strategies for empowering young adults with significant disabilities. Social processes are not made of steel; they can be affected or changed for the benefit of individuals and their lives.

I take the high road, you take the low road... or the wasteland?

Our interviews with the young adults left us with the feeling that each member was travelling along one of two parallel roads or on the wasteland in between. The first group of travellers (group A) seemed to be on the same road as the rest of us -- the road of the mainstream of society. Many experienced a much more bumpy ride than the rest of us, but not always. Two or three travelled at great speed, cruising on the middle of that road.

They were a young man with cancer who is graduating with top grades, a young woman with spina bifida studying journalism, and a young man with paraplegia studying mathematics at the university. They put their effort into excelling at school and succeeded in surpassing most of the other students, those with and those without disabilities.

Most of the travellers on this road, however, were travelling at a much slower speed, nearer to the edge of the road, occasionally falling off but getting back on again. All of the group A members, both those moving fast and those moving slower, had in common that they had been in inclusive or integrated schools for much of their school years. They had learned, to become effective self-advocates. They had real friends, both with and without disabilities, most had at least one parent who stood by them, supported them, and expected them to do their best. These young people all expected that they would eventually reach social acceptance as adults.

The second group of travellers (group C) was on a slow lane. Members of this group were supported a great deal more than the young people in group A. Fewer demands were put up on them, and neither their teachers, nor parents (sometimes), nor they themselves (sometimes) expected much. With two exceptions, these young people felt themselves to be younger than their chronological age.

What they had in common was not necessarily the disability labels, although more people in this group than in group A had a label of mental retardation.

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What they had in common was that they had all been to special schools or special classes, they had all learned to accept their disability in a fatalistic manner and learned to fit (more or less) into the system. Some of these young people were content and happy with their lives. Many lead a full social life (but they had not always planned that social life themselves). Most had friends with disabilities only and moved primarily in segregated settings. Many had non-disabled paid friends (paid support people near their own age) , and a few had only paid friends.

There appears to be a third group, group B, between these two groups of travellers. This group is comprised of a few young people wandering about in what one might call the wasteland. Apart from two young people with autism, members of this group had a variety of labels similar to those in groups A and C. It is unclear what they may have in common in their These people were very able. They seemed to need less physical supports than many of the people in the other groups. They sometimes advocated for themselves, but more often took the fatalistic attitude. Many found it difficult to accept that adulthood could apply to themselves one day, or they saw it ahead at the end of a long hard struggle. Some felt that one or both of their parents undermined them, took too much charge or did not want to have too much to do with them. Many expressed anger at parents, teachers or support persons.

The parents

The parent interviews are currently in progress. Interviewing the parents could turn into a very emotional encounter. One mother, a professional in the social services field, cried and laughed throughout the interview. She was very surprised at her own reaction at talking of events and feelings 16 to 20 years ago. She said; "I do not know why I keep crying, but may be it is because you are the first person to ask me how I felt and who helped us. No one did, we were supposed to know it all; we still are."

Each story was unique and moving. When the interviews have been completed, I will try to do justice to the gifts these parents shared. I have not yet interviewed all the parents, and more mothers than fathers came. Still, it is clear that all the parents who participated in the interviews cared very deeply about their sons and daughters, and all had struggled with professionals, the public health system, social system or the schools on their behalf.

The research team was struck by a number of things during the interviews. Most parents reported feelings of isolation, helplessness and despair at being told by often clumsy professionals about their child's disability. Too many parents remembered exceedingly disrespectful professionals trying to explain their child's label and prospects. A mother of a 19-year-old told this story:

"The doctor was pointing at this bell curve and explained that it was an intelligence curve. He said, 'this is where most people are, this is where bright people are and this is where the chimpanzee is.' 'Where would you put my daughter?' I asked. 'Here,' he said 'next to the chimpanzee!' (Laughter) 'How could he say that? This was a joke to him...I lost all respect for him....'"

How the parents handled "being told," the kind of support they got from the professionals, especially medical and rehabilitation staffs, and from family and friends, highlighted the amount of power parents gave to the professionals, what they themselves took charge of, and when.

Conclusion

This article is a very brief and simplified version of a complicated, long-term study of the world of the young Icelandic adult with disabilities. The study is still in progress. However, it does present two interesting points. First, the level and type of disability label has less impact upon quality of life such as friendship, activities, and one's belief in one's ability to become adult than parental support and expectations, schooling, and whether or not one has friends. Second, the nature of support that parents receive right from the start of life with a child with disabilities contributes significantly to that child's perspectives, quality of life and future prospects.

Dora S. Bjarnason is an Associate Professor at the Iceland University of Education. Professor Bjarnason is Icelandic, and a British educated sociologist. She has been a Visiting Scholar at Syracuse University, The University of Oregon, and in universities in New Zealand and Australia. Professor Bjarnason is currently a Visiting Scholar at the Danish Pedagogical University in Copenhagen.

For more information on this study, contact Dora Bjarnasonby e-mail (dora@khi.is) or (dobj@dpu.dk)

Footnotes

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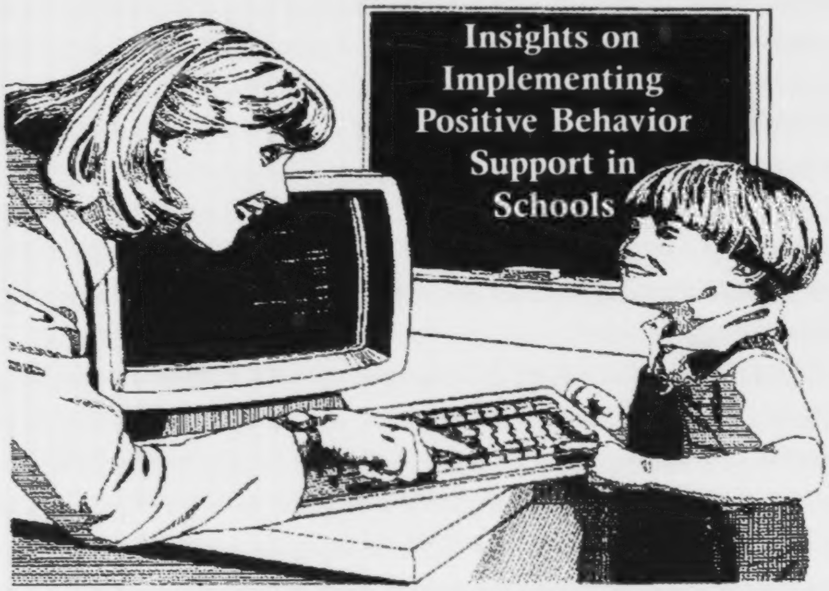
[1] Until 1998 young persons became legal adults at the age of 16. This was changed by law but the idea that one is an adult or close to adult status at 16 is still prominent within the society (law no.74/1997). Only one person in my sample was 16, two were 17 and all the others 18 or older.

[2] I use this definition of adulthood from Bates. The status of adulthood is most often correctly assumed as part of a tacit exchange of complex information through the interactive elements of language and social content and cognitive interpretation of relevant information about age (e.g. appearance, voice, size and so forth.) Bates 1975. This status brings with it certain rights, duties and responsibilities.



Insights on Implementing Positive Behavior Support in Schools

BY TIM KNOSTER, DON KINCAID, JEANNINE BRINKLEY, ANNE MALATCHI, JENNIFER McFARLAND, PATRICK SHANNON, JUDY HAZELGROVE, AND CAROL SCHALL

In the April 2000 issue of the TASH *Newsletter*, the Tri-State Consortium discussed the critical features of a positive behavior support (PBS) approach that had been implemented across the states of Pennsylvania, Virginia, and West Virginia. We described the components of the PBS process and discussed the success of the approach within these three states. We indicated that hundreds of individual teams and a few school-wide teams had experienced success in addressing challenging behaviors of students and in improving areas related to the students' quality of life.

In light of the success of PBS in school settings, it is logical to wonder why it is so difficult to establish positive behavior support for some students in some schools. In particular, why is it that positive behavior support can take root and flourish in some school systems, but wither and die on the vine in others? Knoster, Villa and Thousand (1999) have provided a change process framework that may help us to better understand why this happens, and suggest ways to enhance adoption/utilization of PBS within given schools. The authors describe the presence of "enablers" and "inhibitors" at each step in the change process that correspond to a given team's vision, skills, incentives, resources, and action plan for change. Within the PBS process, it is particularly important to attend to the enablers to the process while successfully managing the relevant inhibitors across settings (e.g., classroom, home, and community factors that may impede implementation of PBS). This article attempts to highlight some critical factors that enable and inhibit the PBS process based upon the Consortium's experiences over the last several years.

What have we learned about critical variables that enable or inhibit the application of PBS for individual students?

Our experiences with PBS, coupled with what has been published in the literature (Hieneman & Dunlap, 2000), suggests that there are a wide range of factors that impact the application of PBS for individual students. The list that begins in the next column highlights what our project has identified as primary "enablers" and "inhibitors" to application of positive behavior support for individual students in schools. It is important to understand that the presence of an inhibitor or an enabler in a given school does not by itself guarantee success or failure of implementation. Rather, inhibitors and enablers provide clear points of focus for facilitators of the change process.

ENABLERS to PBS for Individual Students:

- A sense of urgency usually surrounds events of serious student problem behavior.
- There is a growing literature base of successful experiences in schools.
- There is generalizability of the PBS process across student populations.
- A child-centered focus serves as the foundation and leads to measurable outcomes in the form of reductions in problem behavior, increases in socially acceptable alternative skills, enhancement in quality of life, and consumer satisfaction.
- Educators can relate to the teaching paradigm that serves as the cornerstone in the process.
- Changes in IDEA language emphasize functional assessment and positive behavioral intervention.
- The failure of exclusion and punishment in school settings has been well documented.
- The problem solving process results in interventions that are effective.
- The process provides families and educators with an opportunity to collaborate.
- A support plan can have a broad impact on the life of the student, teachers and family members.
- There are usually logical opportunities to imbed the process for individual students into existing infrastructures and systems in schools (e.g. continuum of assessment procedures in schools).

What have we learned about critical variables that enable or inhibit the application of School-wide PBS?

In a similar manner to supporting individual students (i.e., individual

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Insights on Implementing Positive Behavior Support in Schools

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student teams), "enablers" and "inhibitors" exist relevant to building-based application of PBS for all students. The lists to the right include a number of important points for consideration pertinent to school-wide application of PBS.

INHIBITORS to PBS for Individual Students:

- The initial point of entry for teams is often in response to crisis.
- The process takes time and may require reassigning resources.
- Often schools desire a quick fix/ simplistic reduction of problem behavior.
- There is a general lack of understanding in schools that PBS, while being person- centered, is a problem-solving approach that requires careful management of time, energy and resources.
- Generalization of practice by teams from one student to another typically must be taught.
- There must usually be an initial internal champion and/or external facilitator.
- PBS requires a team approach that may require a long-term commitment from the team as well as facilitators/ trainers.
- Follow through and implementation can be compromised when there is no internal champion who understands the process and philosophy.
- Schools often struggle with establishing proactive interagency approaches.
- Individual teams often struggle with creative problem solving at least, in part, due to traditional decision making hierarchies in schools.
- Mandated changes by school administration in response to the IDEA can result in teams feeling compelled to simply fill out forms as opposed to designing and delivering support.

ENABLERS to School-Wide PBS:

- Building based systems represent a logical extension of PBS for individual students. This approach is sometimes more easily marketed to school administrators who may have greater pressure to address building disciplinary matters as opposed to supports for one particular student.
- Schools are clearly under pressure to do something to address increasing perceptions of society regarding youth violence/disruptive behavior.
- Building-based PBS is also built on a teaching paradigm with which educators can relate.
- PBS takes a long-term view and can positively impact school climate/ culture to facilitate student achievement.
- A school can often have a significant initial impact by targeting prevention strategies based on building data analysis.
- Schools who already have the concept and process of team problem solving in place (e.g., pre referral intervention teams, individual support teams) are well positioned to go to building-wide scale.
- There is an increasing awareness of school-wide approaches in the field.
- Local ownership is fostered as a result of consensus building activities related to identifying and teaching core behavioral expectations to all students.
- Teaching staff typically find building based data helpful for decision making when it is presented in a user friendly format.
- Presentation of information and data on behavior change as a result of school-wide application can be used to enhance communication and public relations with stakeholders (e.g. general public through media coverage).
- Other agencies and community groups are logical collaborators in the process.

INHIBITORS to School-Wide PBS:

- Misperceptions of dichotomy between student "behavior" and "academic performance" (e.g., "If we could just get the kids to behave, then we could teach them").
- A lack of self-reflection at the building level, and in some instances, denial as to the fact that exclusion and punishment will not bring about desired changes.
- Misapplication of "zero tolerance" approaches and society's knee-jerk reaction to media sensationaliza-tion.
- Building-wide approaches by themselves will not be sufficient to support the small number of students that require individual students systems (i.e. 3-7% of students).
- Facilitators of implementation must tend to the process of change for more than one year to sustain and impact the culture. PBS must become "institutionalized" in order to have an enduring impact.
- Helping staff to change their operating set of assumptions regarding the ineffectiveness of reactive procedures such as punishment and helping them to see long-term value in being proactive requires time and effort.
- Durable, significant change requires commitment and administrative support.
- Schoolwide PBS requires that a priority be placed on consensus building concerning behavioral expectations and consistency among staff. Recognizing/ reinforcing expected student behavior requires buy-in from a critical mass of staff.
- Resources and schedules may need to be re-deployed and/or re-aligned to facilitate the teaching of core behavioral expectations to all students.
- Ongoing progress monitoring and planning is required beyond the initiation phase.

Important Changes

Schools are increasingly under pressure to change. In response to this pressure for change, the enterprise of positive

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behavior support has developed significantly in the last few years to assist schools in making changes that impact not only children with disabilities, but all children in all schools. As a result of legislation (IDEA 97), activities of various federal projects, as well as projects initiated by state and local education agencies, there has been significant outreach on PBS in schools. In relation to this outreach, a number of important changes in research, policy, and practice are currently emerging. These changes include:

◇ Changes in policy and practice in schools based on research in PBS. This includes not only research on assessment and intervention, but also research that looks at broader measures of impact beyond simplistic reduction in problem behavior.

◇ Continued growth of self-sustaining training/technical assistance networks across the country. In addition, parents and advocates are increasingly realizing the value of PBS and are requesting that schools implement positive approaches.

◇ State and Local Education Agencies, in response to IDEA 97, have begun to change policy in many states in such a way that training, technical assistance, resources and other supports are being provided at regional, state and local levels. In addition, there has been a corresponding constructive change in belief systems in many Local and State Education Agencies that have the responsibility for providing educational services and programs. Subsequently, a growing number of State Education Agencies are developing policies and procedures that increasingly support and sustain practices (e.g. State Improvement Grants).

◇ PBS has been increasingly acknowledged in both practice and the research literature as effective practice in supporting students with problem behavior across home, school and community settings.

These changes, when viewed in total, are exciting as they serve to establish the parameters for expanded practice in the future. We believe that the foundation of research, policy, and practice exists for increasingly embedding PBS in school systems to better support students with challenging behavior and to positively influence school climate for all students. The next few years will provide an opportunity to apply what has been collectively learned in the field to date, and set the stage for realizing further positive results and future learning.

For more information interested parties are encouraged to visit the Tri-State Consortium's website at www.positiveapproaches.org.

Laura Baker Services Association

Full-time and part-time positions available working with adults with developmental disabilities. Flexible schedule. Various times and shifts now open. Great starting pay and benefits for those who qualify. Rewarding work for the right people. Call or stop in for an application/interview today.

For further information, contact Laura Baker Services Association, 211 Oak Street, Northfield, MN 55057, call (507) 645-8866, or send an e-mail to (www.laurabaker.org)

2000 TASH Annual Conference Special Event

"How Big Is Your Circle?"

A new musical for schools that promotes the healing of exclusion, ridicule, and violence will be performed at 7:30 Thursday evening by an inclusive cast of the Fort Lauderdale Children's Theater.

The musical, by writer and advocate Jeff Moyer, has been hailed by teachers , parents, kids and critics from California to the Virgin Islands. One theater writer who reviewed the work stated, "A noble work that holds great promise in shaping the upcoming generation, this promises to be an important teaching tool for families, youth leaders, and teachers." Run time 1 hour.

Care of Infants and Young Children with Disabilities Worldwide

BY BARBARA KOLUCKI,
Early Childhood Care and Development and Children's Media Consultant to the UNICEF-Maldives Office

Global Trends

Around the world, almost every day in the media one can find something new about the critical importance of the first five years of a child's life. Parents are being told about the variety of things they can do to stimulate their baby's growth and development. There are new magazines being published, new websites, consultative groups to the United Nations agencies, and new international non-governmental organizations (NGOs) and foundations devoting time and money to Early Childhood Care and Development (ECCD). Even advertising for diapers and toys now often contain important messages about ECCD in them!

Much of the new research is basically confirming what parents and practitioners in the field of early child development have known and been practicing for many years. What we have now is new scientific data to support this knowledge and practice.

For example, we now know that:

❖ The years 0-3 are critical in the formation of intelligence, personality, and social behavior, and the effects of neglect are cumulative.

❖ Brain development before the age of one year is more rapid and extensive than previously realized. The brain nearly triples in size within the first year of life.

❖ Brain development is much more vulnerable to environmental influences than suspected. This includes not only nutrition, but also the quality of interaction, care and stimulation.

❖ There is evidence of the negative impact of stress during the early years on brain function. Children who experience extreme stress during the early years are at greater risk of developing a variety of cognitive, behavioral and emotional difficulties.

❖There are proven "windows of opportunity" for learning during the first years of a child's life. If these windows are not opened at the critical time period, it will be difficult, if not impossible, for a particular type of learning to occur at a later time.

❖ Children who have fathers that are involved in nurturing and caregiving often learn better and have fewer social and behavioral problems later in life.

UNICEF's New Priority Area

For UNICEF, and its work with collaborators throughout the next decade (2000 - 2010), one of the key priorities will be Early Childhood Care and Development. Executive Director Carol Bellamy calls it a logical extension "of everything we have done before; it takes us beyond survival. It affirms that a healthy and nurturing environment in the early years brings with it physical, psychological and cognitive benefits which will sustain the child for life. It recognizes that mere physical well-being is not enough. There must be the kind of loving emotional support which brings meaning to childhood."

To this end, UNICEF has established an inter-sectoral working group on young child development that met in September of 1998, followed by a December 1999 meeting on Early Childhood Care in New York City. The Workshop focused on programming that has been initiated by several UNICEF Country Offices, particularly those highlighting 1) the central role of families; 2) the supportive role of communities; 3) enabling national environment and; 4) communication and advocacy. Program guidelines on Early Childhood Care, as well as Tools for Assessment, were also discussed.

In 1995, "*Growing and Changing: A Guide to Early Childhood Development for Parents,*" a series of four 10-minute animated videos and guidebooks, was produced by UNICEF. The series covers basic information on normal child development and simple ways a caregiver

In many western countries, early intervention programs for infants and young children with disabilities have been in place for the past 25 years. Identification of a disability at birth or soon thereafter has allowed for the youngest infants to be placed in a program where they are nurtured and stimulated, together with addressing their medical needs and the emotional needs of their family.

What is important to note is that these programs have been doing for many years exactly what is being presented today through the media as new information for children without disabilities.

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Care of Infants and Young Children with Disabilities Worldwide

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can nurture skills in language, social, emotional, physical and motor development. The material is available in English, French, Arabic and Spanish through UNICEF. Some countries, including Lebanon and Turkey, have already re-packaged the videos together with live-action segments from their country.

Infants and children with disabilities

Babies are born with physical, social and psychological capacities allowing them to communicate, learn and develop. This is true for all infants, including those with disabilities. What might be different is the limited or lack of use of a particular sensory organ or a physical disability of one type or another like cerebral palsy or a club foot. Or, the child might have a cognitive disability. But even a child with the most significant disabilities can learn. If the child's capacities are not recognized and supported, these capacities will wither rather than grow and improve.

How does some of the new research relate to infants and young children with disabilities? What is unique to babies with disabilities and what are the implications for early intervention? Here is a summary of some disability specific information that should be shared with laypersons and caregivers around the world:

❖ The greater the degree of sensory deprivation for an infant (visual, hearing, movement) and the longer it lasts, the more permanent the impairment or disability.

❖ Even in the case of sensory deprivation, it is not only the particular sense that might be compromised, but also cognitive, social and emotional development.

❖ For some disabilities, the timing for intervention is critical. Simple surgery, treatment or exercises is usually much more successful if it is done in the first years of a child's life. For example, a cataract should be removed from an infant before the age of six months. Other types of surgery are usually recommended between the ages of 6 to 18 months.

❖ It is not uncommon for some disabilities to go unnoticed unless parents are aware of what to look for. For example, many children are not identified as being deaf or hearing impaired until the age of two or older. Most babies with hearing difficulties coo and babble, so unless the baby's hearing is checked regularly, or a parent notices that the baby does not react to loud sounds, it is not noticed until the time most babies begins to speak. Since hearing is connected to every other aspect of development, however, it is important to make an early identification. Children who are introduced to sign language early usually do better (academically, socially, as well as in the complexity of use of sign language communication), than those who do not learn it until they enter primary school. In addition, some children can benefit from hearing aids.

❖ The sequence of skill acquisition is sometimes affected when a baby has a disability. A child who is blind might experience delays in walking but not in sitting. Because of lack of visual stimulation, as well as a self-protective fear, many babies who are blind will be less motivated to move and explore.

❖ Babies' brains are vulnerable to stress. Children who are in situations of war, violence, and abuse, especially in the first three years of life, can develop brains that are visibly smaller. Children in stressful situations of this nature also tend to suffer from emotional problems.

❖ Because we know that experience affects the size and structure of the brain, it is imperative that children who are diagnosed with a disability receive as rich and stimulating an environment as possible.

Disability specialists lead the way

In many western countries, early intervention programs for infants and young children with disabilities have been the norm for the past 25 years. Identification of a disability at birth or within the first months of life has allowed for the youngest infants to be placed in a program where they are nurtured and stimulated, together with addressing their medical needs and the emotional needs of their family. Cutting-edge programs exist to train parents on what they can do at home, specific techniques with regard to caregiver-child interactions based on disability-specific rehabilitation, and play situations where young children with disabilities can learn developmental and social skills. The overall opinion is that these programs have been and are effective. What is important to point out is this: these programs have been doing for many years exactly what is being presented today through the media as new information for the parents of infants and young children without disabilities. In fact, disability specialists have a lot to teach all of us working in the field of Early Childhood Care and Development.

What happens, however, to the majority of infants and young children with disabilities in the world -- the nearly 80% that live in developing countries? It is true that many are cared for and loved by their families as much as any child in the world. There are numerous families that instinctively know what to do, how to adapt, and the importance of integrating their child into family, school and

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Care of Infants and Young Children with Disabilities Worldwide

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community life. There have been pioneers, too, that have brought early intervention projects to countries like Jamaica, Guyana, Malaysia, the Philippines, India and others. These projects are exceptional and some have spawned "satellites" to more rural, isolated areas. And more community-based rehabilitation (CBR) programs that were originally designed for adults with disabilities now include a component for children.

Working uphill against ingrained attitudes

Having worked in over a dozen countries, mostly in developing parts of the world, I find that a major challenge to reaching infants with disabilities in their earliest days is the deeply instilled social attitudes that lead to these children being hidden and isolated. Even with advances in many parts of the world, there are still millions of people who have never seen a positive portrayal of a child or adult with a disability in a book, television program or film. They might not have ever met an independent person with a disability. If a parent believes that his child cannot learn, will not be able to study, will never marry or hold a job, then it might seem reasonable to the family or caregiver to simply love that baby and care for the child's basic needs. The low expectations for infants and children with disabilities leads to their being spoken to less, played with less, taken outside the home less, stimulated less, and educated less.

Basic information

We must remember that that early intervention program need not be expensive to make a difference in the life of a young child with a disability. All parents of infants and young children with disabilities can make good use of the following information:

- Every infant, whether or not he or she has a disability, can benefit from nurturing and stimulation of the senses. The more a child is spoken to, sung to, read to, danced with, exercised and played with, and encouraged to explore in a safe environment, the more the brain and body will develop.

- The earlier a disability is detected, the more a child can benefit from both rehabilitation, as well as simple interventions that help maximize abilities and potential.

- There are simple things a parent can do to detect a disability in their young child. These include: holding a brightly colored cloth or toy on one side of a baby's face and watching to see if the infant follows it to the other side with her/his eyes; standing quietly behind a baby and then clapping one's hands or slamming a door to see if the infant makes a startled motion; noticing if a baby at around age three months can lift her/his head when placed on her/his stomach; smiling at a baby and watching to see if the baby responds by smiling, cooing, and/or looking back. Most parents and grandparents know what other children have done around a particular age; they already have a skill in early detection!

- There are simple things that can be done in any home to enrich the baby's environment. These include: safe, tactile toys; brightly colored or black and white mobiles; labeling objects and actions; infant massage that includes talking with the baby, naming body parts and responding to the baby's cues; encouraging the baby to communicate in whatever possible way; and guiding touch and movement.

- All children need and will benefit greatly from continuous contact with caring adults and children their own age. The more children and adults with disabilities become visible in the community, the more they will be joined by others with disabilities who now see they are welcome in the community.

Conclusion

The Convention on the Rights of the Child (CRC) includes the right of children with disabilities to equal opportunities, as well as to have their disability detected and treated as early as possible. The UNICEF Mission Statement includes a commitment to ensure special protection for children who are most disadvantaged, including those with disabilities. The new focus and priority attention to Early Childhood Care and Development (ECCD) must also include infants and young children with disabilities. The families of these children must be included, as well. This cannot be seen as a specialized or add-on component of ECCD, but one that is integral to ECCD. It is not only absolutely critical, but it is possible for every program, every product and every country to include infants and young children with disabilities. This is a moral and ethical imperative that will, as the research tells us, positively or negatively affect the lives of millions of children in the world.

References:

Rethinking the Brain: Early Child Brain Development, a presentation kit from the Families and Work Institute, N.Y.

"What's Going On In There," published by Bantam Books.

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TASH Committee Meetings

2000 TASH Conference
moving the edge
Miami Beach, Florida · December 6-9th

To assist with planning your schedule for the upcoming TASH conference, we have provided an advance list of the auxiliary and committee meeting schedule. Please note that not all events have been finalized.

Auxiliary and Committee Meetings

Chapter Operating Committee	Thursday, 7:30 - 8:30 a.m. in the Imperial IV Room
Communications Committee	Friday, 5:15 - 6:15 p.m. in Conference Room 5
Conference Planning Committee	Saturday, 12:30 - 1:30 p.m. in the Club Atlantic Room
Employment Committee	Friday, 7:00 - 800 a.m. in the Bordeaux Room
Education Committee	Friday, 7:00 - 8:00 a.m. in the Club Atlantic Room
Future Conference Site Selection	Thursday, 6:00 - 7:00 p.m. in Club Atlantic Room
Governmental Affairs Committee	Saturday, 9:00 - 10:00 a.m. in Conference Room 1
JASH Editorial Board	Friday, 1:00 - 2:00 p.m. in the Grand Ballroom
JASH Associate Editors	Friday, 2:00 - 4:00 p.m. in Conference Room #4
Membership Committee	TBD
Multicultural Committee	Thursday, 1:00 - 2:00 p.m. at the Roundtable Luncheon
Publications Committee	TBD
TASH Board Meeting	Tuesday, 12:00 - 7:00 p.m. Saturday, 11:15 a.m. - 4:00 p.m.
TASH Open Forum	Thursday, 1:00 - 2:00 p.m. in Monaco Room
Sexuality Committee	Thursday, 1:00 - 2:00 p.m. at the Roundtable Luncheon
Spirituality Committee	TBD
Personnel Preparation Committee	Friday, 5:15 - 6:15 p.m. in Imperial I
Positive Approaches Committee	TBD
Whole School Consortium	Thursday, 4:45 - 7:00 p.m. in Monaco Room

Universal Primary Education in Uganda

BY ALEX NDEEZI

Uganda's Universal Primary Education (UPE), begun in 1996, is the brain child of President Yoweri Museveni. A former lecturer at the University of Dar-es-Salaam, Tanzania, Museveni is one of Africa's pragmatic leaders who believes in the transformation and modernization of society through the elimination of illiteracy and the provision of education for all – irrespective of one's gender, ability or any other categorization.

In practice, the Universal Primary Education program is not universal, but has a realistic tendency towards universality. Before implementation, the policy was extensively discussed at various fora, including educational institutions, in the cabinet and at the parliamentary level. Under this program, the government commits itself to providing primary education for a maximum of 4 children per family. In order to comply with Uganda's constitutional requirements on affirmative action in favor of marginalized groups, 2 of the 4 must be girls if a family has children of both sexes. In addition, if a family has a child with disability, he or she must be granted the highest priority in enrollment under this program.

The government pays the school fees for the children. It also provides grants to be spent on instructional materials, extracurricular activities like sports, and the management and maintenance of utilities like water and electricity. By the end of September 1999, six and a half million children aged 6 to 15 had enrolled for primary school education -- one third of Uganda's total population. Total enrollment rates for all children have tripled since 1996, and the enrollment of children with disabilities -- almost half of whom are female -- has quadrupled.

Challenges

The increase in funding has helped to reduce the illiteracy rate – especially among children with disabilities. There has also been increased awareness of the educational needs of children with disabilities, including the need for sign language development.

However, the increase in enrollment rates has brought to light the enormous challenges of providing education for all children, and the particular challenges of providing education to children with disabilities.

Challenges

The Universal Primary Education policy emphasizes the mainstreaming of all categories of children. However, those labeled as profoundly deaf are not yet benefiting from the program. Because the emphasis is on day schools, children with visual and physical disabilities are finding it increasingly difficult to travel for long distances to and from school on a daily basis.

Mobility aids like crutches, wheelchairs and white canes are not provided for in the program. Neither is the physical environment in most schools accessible. Special education teachers skilled in areas such as deaf education, sign language, and visual and mental disabilities are inadequate or non-existent in most primary schools. The classrooms are always too congested. In some areas classes are conducted under mango trees.

The program has been criticized for being short-sighted. It does not explain what will happen to the tens of thousands of children after primary level. The current ratio of teacher to pupil is 1:110. This is extremely high, and not conducive to proper learning and good standards. With this ratio, the children with disabilities who need additional support simply get "swallowed" in the congested classrooms.

The negative attitudes of most teachers towards children with disabilities are in many respects still a hindrance to the success of the program. The program has almost become too expensive to run because the government is short of funds. The result is that donors have been approached for assistance. However, these donors often come in with their own conditions, which may not be wholly in the interests of the children or the program.

The Way Forward

There is a need for grants for children with disabilities to enable them to acquire mobility aids and other needed learning materials. The Ministry of Education has already issued a directive on ensuring physical accessibility for children with disabilities in the construction of new buildings. Some schools have already started implementing this directive.

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Universal Primary Education in Uganda

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Even though the Universal Primary Education program has some weaknesses and faces some challenges, it has been hailed worldwide as a wonderful program, a reflection of political commitment to education for all, and a role model of how the poorest countries of the world, such as Uganda, can eliminate widespread illiteracy and develop their human resources by provision of affordable education.

Alex Ndeezi is Uganda's first deaf member of Parliament. He is also the chairperson of the Uganda National Association of the Deaf. Mr. Ndeezi may be contacted at: PO Box 7339, Kampala, Uganda.

Silent AUCTION EVENT

There is still time to share the tastes, sights and sounds of your favorite places with others who may not have a chance to journey to your corner of the world! Make a donation to the TASH Silent Auction today!

Join with the Anchorage Convention & Visitors Bureau, the Baltimore Orioles, Blockbuster Video, Justin and Yoshiko Dart, Diverse City Press, Hard Rock Cafe, Hilton Anaheim, PEAK Parent Center, Reno Hilton, Van Gogh Music, TASH chapters, and other supporters by making a donation to this exciting event. Proceeds from the auction will benefit the TASH Conference Scholarship Fund. The Fund is used to assist people with disabilities, parents and other family members to attend future TASH conferences.

If you would like to make a donation or find out more details, please contact Priscilla Newton, Director of Marketing, at 410-828-8274, ext. 102; send an e-mail to (pnewton@tash.org); or visit TASH's web site at (www.tash.org)

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TASH NEWSLETTER

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TASH Newsletter

VOLUME 26 ISSUE NUMBER 11 NOVEMBER 2000

Early Childhood

Inside: Variables that Contribute to Self-Determination in Early Childhood; What Children and Families Need in Health Care from Birth through Adulthood; Re-thinking Guardianship; and Increasing Learning Opportunities for Children

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

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The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

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Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

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From the Executive Director
BY NANCY WEISS

TASH, Other Rights' Groups, Combat the Use of Aversives

TASH was the first national disability organization to take a position against the use of aversive procedures and this issue continues to be a major focus for TASH. Examples of aversive procedures include the use of electric shock, water spray, visual screening, prolonged restraint/isolation, and taste aversives in response to behaviors judged to be unacceptable. TASH always has been, and continues to be, unequivocally opposed to all use of aversive procedures.

Although some people have believed that such procedures are necessary to control dangerous or disruptive behaviors, it has now been irrefutably proven that a wide range of methods are available which are not only more effective in managing dangerous or disruptive behaviors, but which do not inflict pain on, humiliate, or dehumanize individuals with disabilities. Alternative approaches that are proven to be effective attempt to identify the individual's purposes in behaving as he or she does and offer support and education to replace dangerous or disruptive behaviors with alternative behaviors that will achieve the individual's needs.

People with mental retardation and other disabilities make up one of the most devalued segments of the population. Abuses are imposed on them which would not be tolerated if they were applied to the elderly, school children, prisoners, or even animals. It is clear that individuals with disabilities who act in ways that are dangerous deserve at least the same protections afforded prisoners against cruel and unusual punishment. Additionally, they have a right to treatment that is both humane and effective.

In recent weeks TASH has taken a number of important steps toward the goal of eliminating the use of painful stimuli to reduce behaviors that are deemed unacceptable. A group of TASH members (including Rick Amado, Fredda Brown, Dick Cohen, Anne Donnellan, Gary LaVigna, Jeff Strully, and myself) have drafted a statement on aversives to be included in the reporting requirements for two United Nations Covenants on human rights. We have been working closely on this issue with principals from two other international human rights organizations, Mental Disability Rights International and Physicians for Human Rights.

Eric Rosenthal of Mental Disability Rights International invited TASH to draft this statement on aversives to be included in reporting requirements for two of the most important United Nations international human rights conventions - the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social, and Cultural Rights. If accepted, this will mean that for the first time, every country that has endorsed these two United Nations Covenants will be required to report to the U.N. on the use of aversives in their country just as they are required to report on other human rights abuses.

There is no question that some people with disabilities have behaviors that are dangerous or seriously disruptive. Some people (both with and without disabilities) exhibit behaviors that interfere with the quality of their lives and the lives of the people with whom they interact. We have a responsibility to offer supports for people to change behaviors that are dangerous, disruptive or interfere with their ability to achieve their goals for themselves. Our responsibility, however, is to do this in ways that value, enhance and include people.

In addition, the TASH Board recently approved a new resolution on the use of aversive procedures. This resolution clarifies TASH's uncompromising stand against these techniques. The text of that resolution is included on page 6.

In addition to the work on the U.N. statement and the new resolution, TASH recently convened a historic meeting to explore various approaches toward the elimination of aversive procedures. At TASH's invitation, representatives from the American Association of University Affiliated Programs, the American Association on Mental Retardation, the American Psychological Association, the American University Law School, Amnesty International, Arc-US, The Autism National Committee, the Joseph P. Kennedy, Jr. Foundation, Mental Disability Rights International, the National Association of Protection and Advocacy Systems, Physicians for Human Rights, the President's Committee on Mental Retardation, and Senator Wellstone's Office (Minnesota) were in attendance. Options discussed included federal legislation, strengthening state and federal regulations, initiating one or more human rights investigations/reports and encouraging more media coverage.

TASH affirms the right of persons with disabilities to freedom from aversive procedures of any kind. TASH is unequivocally opposed to the use of aversive procedures under any circumstance and calls for the cessation of the use of all such procedures.

Continued on page 5

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TASH, Other Rights' Groups, Combat the Use of Aversives

Continued from page 4

Finally, there are a few related efforts underway aimed at collecting information on the use of aversives from a number of perspectives:

○ We are trying to gather as much information as possible on different states' laws and regulations on the use of aversive procedures. The issue is a complicated one because many states have protections for people in the developmental disabilities system but not for those in the mental health system; for children but not adults; for residents of state-run institutions but not for those served in community programs, etc. If you have access to your state's laws or regulations about the use of aversives or restraints please send a copy to me (see contact information in the next column).

○We also are trying to gather current position statements on the use of aversives from as many national organizations as have them and to encourage those that don't to consider adopting such a position. If your group, or a group with which you are affiliated has such a statement please send me a copy or let me know whom I should contact to obtain a copy. If your group has not taken a position against aversives and would like TASH's support to help them to draft a statement of this kind, I will be happy to assist.

○ Additionally, we are collecting specific examples of the use of aversive procedures. If you have personal knowledge of instances in which aversive procedures are being used or have been used recently (in the last five years or so) to control the behavior of a person with a disability, please send me a short description of the incident(s). Include information on the type of setting, the state in which this occurred, when it occurred and whether use of these techniques was part of an a formal program.

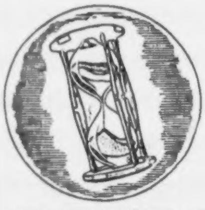
○ Another part of this effort is the collection of information which would document whether the use of aversives is a problem that is restricted to the U.S. or whether this is an international issue as well. If you have information regarding the use of aversive techniques in countries other than the United States or on laws or regulations prohibiting/restricting the use of aversives in other countries, please forward this information as well (or let me know if you have a suggestion of someone else to contact) so we can start to document the extent of the situation worldwide.

○ Finally, TASH has long served as a clearinghouse for reporting on the use of aversives and restraints. If you know of specific situations in which these techniques are continuing to be used, please contact me as well. We now maintain a resource directory of people in every state and in almost every Canadian Province who can assist in finding expert assistance in the development of positive behavioral approaches.

It is hoped that through all of these means, TASH will establish the full arsenal of information needed to eliminate the use of aversive procedures permanently. I have always thought it a sad commentary that there are Federal laws in the U.S. that protect animals from cruel behavioral training techniques but none that protect people. It is our goal to see broad Federal legislation enacted that will eliminate behavioral techniques that are cruel and dehumanizing. I invite your participation in this effort.

Nancy Weiss can be contacted by phone (410) 828-8274, ext. 101, by e-mail (nweiss@tash.org), or by fax (410) 828-6706. For more information about the use of aversive procedures contact Nancy for a copy of her comprehensive report on this topic.

Continued on page 6



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send an e-mail to
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TASH RESOLUTION ON THE USE OF AVERSIVE PROCEDURES

Throughout the world, individuals with disabilities are victim to what are termed "aversive interventions" to control behaviors that are associated with their disabilities. Aversive procedures use painful stimuli in response to behaviors that are deemed unacceptable by their caregivers. All aversive techniques have in common the application of physically or emotionally painful stimuli.

These techniques are inappropriately used, not only to control dangerous behaviors, but also to modify behaviors that are simply idiosyncratic (moaning or twisting one's hair), unusual (tics or rocking) or are inconvenient to caregivers (getting out of one's assigned seat or refusing to perform a task).

When an individual is at imminent risk of hurting him/herself or others, brief physical restraint to prevent injury may be necessary. Brief physical restraint under these circumstances is not treatment. It is used to assure safety in an urgent situation. Treatment is meant to reduce or prevent further occurrence of the behavior by increasing the individual's competence in dealing with the circumstances that provoke the endangering behavior. Individuals with disabilities who act in ways that are dangerous deserve at least the same protections afforded prisoners against cruel and unusual punishment. Additionally, they have a right to treatment that is both humane and effective.

Aversive procedures are often used as part of a systematic program for decreasing certain behaviors. They are used without the consent of the victim and typically, without the informed consent of a guardian. Aversive procedures have some or all of the following characteristics:

♦ Obvious signs of physical pain experienced by the individual;

♦ Potential or actual physical side-effects such as tissue damage, physical illness, severe physical or emotional stress, and/or death;

♦ Dehumanization of the individual;

♦ Significant discomfort on the part of family members, staff or caregivers regarding the necessity of such extreme strategies or their own involvement in such interventions;

♦ Obvious repulsion and/or stress on the part of observers who cannot reconcile such extreme procedures with acceptable standard practice;[1]

♦ Rebellion on the part of the victim against being subjected to such procedure;

♦ Permanent or temporary psychological or emotional harm.

The types of aversive procedures used on persons with disabilities include, but are not limited to:

- Electric shock applied to the body (e.g. arm, leg, or hand) for the purpose of discouraging the specific behavior it follows by causing pain [not to be confused with electroconvulsive therapy (ECT) used to treat severe depression; a procedure that is also subject to misuse]
- Extremely loud white noise or other auditory stimuli
- Forced exercise
- Shaving cream to the mouth
- Lemon juice, vinegar, or jalapeno pepper to the mouth
- Water spray to the face
- Placement in a tub of cold water or cold showers
- Slapping or pinching with hand or implement
- Pulling the hair
- Ammonia capsule to the nose
- Blindfolding or other forms of visual blocking
- Placement in a dark isolated box or other methods of prolonged physical isolation
- Ice to the cheeks or chin
- Teeth brushed or face washed with caustic solutions
- Prolonged restraint through manual or mechanical techniques (e.g. face-down four- or five-point restraint using mechanical tie-downs or several staff applying physical pressure)
- Withholding of multiple meals/denial of adequate nutrition

Although it has been believed that such procedures are necessary to control dangerous or disruptive behaviors, it has now been irrefutably proven that a wide range of methods are available which are not only more effective in managing dangerous or disruptive behaviors, but which do not inflict pain on, humiliate, or dehumanize individuals with disabilities. Alternative approaches that are proven to be effective attempt to identify the individual's purposes in behaving as he or she does and offer support and education to replace dangerous or disruptive behaviors with alternative behaviors that will achieve the individual's needs.

THEREFORE BE IT RESOLVED, THAT TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field, affirms the right of persons with disabilities to freedom from aversive procedures of any kind. TASH is unequivocally opposed to the use of aversive procedures under any circumstance and calls for the cessation of the use of all such procedures.

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[1] *TASH (formerly, The Association for Persons with Severe Handicaps. (1986). Resolution on the Cessation of Intrusive Interventions.*

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VARIABLES THAT CONTRIBUTE TO SELF-DETERMINATION IN EARLY CHILDHOOD

BY ELIZABETH J. ERWIN, Ed.D. and FREDDA BROWN, Ph.D.

Much has been written on the topic of self-determination and its importance to the quality of life of individuals with significant disabilities. However, we have seen much less attention paid to this topic when referring to young children with disabilities. Brown and Cohen (1996) suggest that many programs for young children with disabilities reinforce compliance with teacher directives as opposed to providing opportunities for children to practice choice-making, problem solving, and other behavioral skills essential for self-determination. Other authors have used the term "democracy" to describe that sense of empowerment and freedom that should be available to young children in their day to day lives (Erwin & Kipness, 1997; Greenberg, 1992; Hendrick, 1992). Both the concepts of self-determination and democracy acknowledge the critical importance of ensuring that young children, regardless of ability, are active participants in making age appropriate and meaningful decisions regarding their own lives.

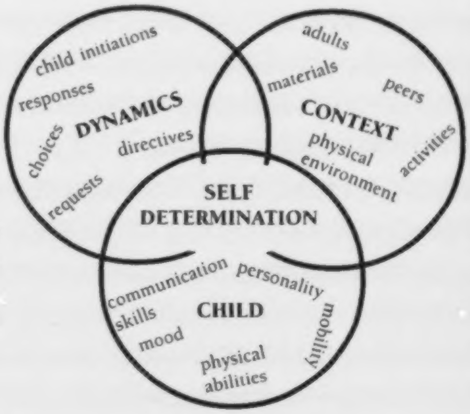
Because self-determining young children would most likely lead to empowered, self-determining adults, it seems logical to explore self-determination issues in the early childhood years. Perhaps an early step in this effort is to further define what self-determination might look like in early childhood settings for young children with and without disabilities.

Identification of key variables, interacting influences, and operationalizing the concept as it pertains to early childhood settings are important first steps in the conceptualization of research.

Three foundations, or assumptions, were at the base of our effort to operationalize the concept of self-determination. First, we felt that self-determination could not be viewed in isolation; it is a concept that must be contextually described. Self-determination is not a single act or behavior. It is, to some degree, a function of, and enmeshed within a complex set of interacting variables. Second, self-determination is a dynamic phenomenon; self-determining behavior is not static. It changes across time as the context and the internal motivations of the child changes. The final assumption suggests that self-determination is influenced by the nature, disposition or personality of an individual child. Each child brings to the world a unique set of characteristics. Recognizing and understanding these unique characteristics will allow us to support and facilitate an individualized and unique path of self-determination beginning in early childhood.

> *Identifying the states, traits, and skills and abilities of a child are an important link in creating a full and meaningful picture of self-determination in young children. Each child brings to the world a unique set of characteristics. Recognizing and understanding these unique characteristics will allow us to support and facilitate an individualized and unique path of self-determination beginning in early childhood.*

Self-Determination is a Function of a Complex Set of Interacting Variables



Conceptual Framework

Our understanding of self-determination in young children has been shaped by three variables: context, dynamic, and the child. Because of the constant ebb and flow of daily life (e.g., people, places, events, and child-related characteristics), opportunities for self-determination, as well as obstacles to self-determination, will constantly change. The following variables provide a framework for understanding the complexities that contribute to self-determination in young children.

Continued on page 9

Variables That Contribute to Self-Determination in Early Childhood

Continued from page 8

Context

Just as it is widely acknowledged that no two children are the same, it is also widely accepted that no two learning environments are the same. Because of differences within the organization, structure, and energy in a classroom, it is important to identify the environmental variables that can impact on self-determination opportunities. There are numerous environmental variables that not only vary from classroom to classroom, but also vary within any one classroom across the day, the week, and the year. Examples of such variables include: (a) number of adults present, (b) number of children present, (c) type of activity, (d) materials, (e) places, and (f) activity format (e.g., large group, small group, individual).

These variables naturally have an impact on opportunities to be self-determining, or in some cases, present obstacles to efforts of self-determination. For example, the game of 'Simon Says' may present different, and perhaps fewer, opportunities for encouraging self-determination than a game or song such as "If You Are Happy And You Know It". Or, a large group activity may be easier for some children to initiate certain types of behaviors that may be consistent with self-determination. Yet for other children, a small group or 1:1 situation may make such initiations easier. Understanding those contextual conditions that promote self-determination and those that may challenge self-determination for each child would allow us to structure classrooms in more informed and supportive ways.

Dynamics

There are numerous variables to consider related to the dynamics of what is occurring within a classroom environment. The initiation or response to opportunities for self-determination play a large role in creating an on-going story of what happens and why within a classroom setting. When a child initiates an act of self-determination, it may either be supported or not-supported by others in his or her environment. How others respond will either contribute to supporting self-determination (e.g., "I see you would like to play in the sandbox. Go right ahead!"), or attempt to prevent self-determining behavior (e.g., "Please sit in your seat now; it is not time to play in the sandbox."). A challenge to educators is to support self-determination even when circumstances present obstacles ("I see you would like to play in the sandbox. Would you put our picture of sandbox on our daily schedule? — Then, when we're finished with our story, we can play in the sandbox.").

A child may respond in a self-determined way to a stimulus (e.g., a directive, choice, or request) presented by an adult. The child's response (e.g., to cooperate, not cooperate or ignore the instruction given) then provides a context for the adult's subsequent behavior. Again, the adults' behavior will either support or present an obstacle to the child's self-determining behavior. That is, adults will either perceive the child's behavior as "initiation" (and likely reinforce self-determination), or judge the behavior as "non-compliant" (and likely discourage the self-determining act).

In addition to adults within the environment (e.g., teachers, assistants, related service providers, parents, volunteers, etc), peers also provide stimuli (e.g., directives, choices, requests) to the child. These stimuli lead to some kind of response from the child (e.g., to cooperate, not cooperate, or ignore) which provides the context for the peer's subsequent behavior. There are many variables and dynamics that define the context in which self-determining behaviors occur. These dynamics, braided together, present a story of self-determination within a classroom. Perhaps the story can be best described as a continually changing narrative -- with opportunities for self-determination, as well as obstacles to self-determination, continually and naturally, weaving in and out throughout the day. We can, however, influence this narrative.

In addition to variables of context and dynamics, there is one more critical variable, the child, to consider when painting a broad and colorful picture of self-determination.

Child

A child's disposition will naturally have a dramatic impact on our understanding of self-determination since no two children are exactly alike. Self-determination is likely influenced by at least the following three variables: (a) states, (b) traits, and (c) skills/abilities. States refer to feelings (e.g., happy, angry) or moods (e.g., cranky, tired) or other conditions of being (e.g., hungry, sick) which impact on a child's behavior. These states are constantly changing. The impact of these types of events is discussed extensively in the positive behavior support literature. The term "setting events" refers to those external conditions that influence the child's perception of the current environment and his behavior. For example, Carr and his colleagues (Carr, Reeve & Magito-McLaughlin, 1996) describe the scenario of a child given an instruction to button up his coat. Under typical circumstances the child may quickly comply with the request. However, if the child has a cold, he may display uncooperative behavior when given the request. In this scenario, the uncooperative behavior might be a function of the setting events --- that is, the illness.

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Variables That Contribute to Self-Determination in Early Childhood

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Traits are characteristics that contribute to a child's personality (i.e., flexible, shy). A child's individual personality and disposition will likely play a part in how a child perceives and ultimately responds to a particular situation. For example, a child who tends to be very energetic and active may perceive a teacher's direction to sit down for circle time as threatening or controlling. Another child in the same class could be given the same direction by the same teacher and under the same conditions, but could perceive the situation in a much different way -- perhaps as a prelude to an exciting event. These two children might respond to the teacher's direction in a very different way because of how they perceive the teacher's instructions. How they perceive the teacher's instructions may be based on the states and traits that make up their individual dispositions.

The skills and abilities a child uses within the classroom and other natural environments will play a large part in the type and frequency of opportunities a child has to be self-determining.

In addition, the states and traits of children tend to reflect who they are and how they participate in the world. A child who is shy, for example, may be more likely to comply with peer or teacher directives as opposed to a child who tends to be more outgoing and spirited. A child who has high self-esteem might generally be more comfortable expressing her needs and desires than a child who might not feel as self-assured. In addition, if a teacher does not respond to a self-determining behavior (e.g., "I want to use the bathroom now") made by a child with high self-esteem, the child may likely attempt additional ways of getting his needs met (e.g., asking another adult, crying, repeating the request). It is not as likely that a child who is very timid or shy would try multiple ways of getting his needs met after a teacher does not respond to a request.

The third child-related characteristic that has an impact on self-determination has to do with a child's skills and abilities. The skills and abilities a child uses within the classroom and other natural environments will play a large part in the type and frequency of opportunities a child has to be self-determining. For example, the way a child communicates will determine, to a large degree, how others interact with her. Certainly a child who is nonverbal and cannot easily use an alternative communication system will have a different experience "being heard" than a child who can call out a request. Mobility is another type of skill that will influence self-determination in young children. A child who is visually impaired or a child who uses a wheelchair may not move as freely from one activity to another during center time. Therefore, participation in self-determining behaviors such as choice-making might be more restricted than for a typically developing child. Understanding the impact of these characteristics on access to opportunities for self-determination should help us facilitate the needed supports.

Identifying the states, traits, and skills and abilities of a child are an important link in creating a full and meaningful picture of self-determination in young children. Each child has a set of unique and individual characteristics that interact with two other variables, context and dynamics that contribute to self-determination in early childhood.

There are many variables that influence self-determination in early childhood settings. These variables are constantly changing as a function of the changing context, dynamics, and child characteristics that naturally occur. We hope that by better understanding these variables we can be more reflective and intentional in our support of self-determination in young children with severe disabilities.

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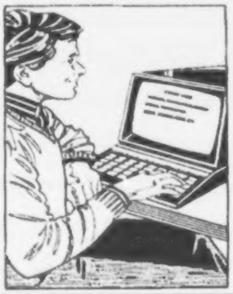
What Children and Families Need in Health Care from Birth through Adulthood: One Parent's Experiences and Advice

BY KRIS SCHOELLER



My son Christian was born a robust and healthy nine-pound boy with an Apgar score of 10. Within four months of his birth we were thrown into the world of neurology, psychology, pneumoencephalegrams, CAT scans, MRIs, multiple medication options and many, many hours in hospitals and clinics. Christian was having seizures identified at the time as psychomotor, now called complex partial. Throughout his childhood and adolescence he would experience every type of seizure, including status epilepticus. I was a 24-year-old, uneducated, first-time mother. Although I was confident in my ability to parent and excited about the role of motherhood, I was in no way prepared to deal with the emotional, psychological, and educational demands of making responsible decisions for Christian.

Christian's first medical, therapeutic, and educational teams were very supportive. For them, parents were equal team members in every decision that was made about programs, services, and events. I appreciated their advice as they emphasized the importance of allowing him to participate in any childhood activity; my first pediatrician said, "The scars from falling during a seizure will heal, the scars from keeping him from activities will never heal." I appreciated the fact that his neurologist wasn't embarrassed to feel and show emotion, like the time he greeted us in the hospital hallways with excitement and genuine care when the good news came about no tumors and no major brain scarring. And I valued the support of the director of the preschool as she held monthly meetings with parents to teach us how to take care of ourselves and to celebrate the accomplishments. Even after moving from Wisconsin to Minnesota and then to Massachusetts, I continued to consult with this original team for support.

The middle years were extremely difficult. Our family moved several times and establishing new teams was grueling. Christian experienced months of overmedication and a loss of language. I blamed myself for lack of knowledge. His medical team pushed beyond his and my limits. One experience led to leaving the hospital against medical advice (AMA). The original MRI machines were designed to hold the head in place. Christian had such fear of the procedure that the decision was made to medicate him. After four hours in the radiation waiting room and enough medication to put a grown man to sleep, Christian continued to fight. I looked at him and saw that intense fear and cry for help, and I knew that if I allowed them to continue to inject more medication, I would kill his spirit. I picked him up off the cart and carried him out AMA.

I had to learn how to trust my own intuition and knowledge. I studied many hours each week about neuropsychology, the function of the brain, the impact of sensory integrative therapy and patterning. I had to learn to read and understand the Physician's Desk Reference. I took night classes in educational law and writing IEP's (Individual Educational Plans).

When he was seven years old, Christian's teachers and therapists said he was very inappropriate socially. One physician wanted to label Christian as psychotic and place him in a school for children with psychiatric disorders and prescribe additional medication. I felt that his anger and frustration was due to lack of any success or verbal encouragement. Christian and I flew back to Minnesota to that original team for further evaluation. We received a diagnosis of Early Onset Pervasive Developmental Disorder. Returning home, we filed due process challenging the schools for appropriate placement and understanding of Christian's disability. We struggled with a $10,000 attorney fee and months of emotionally-charged legal battles. At the same time I was pregnant with our fourth child.

> ***Research supports that parents learn the most from other parents. They speak the same language, have immediate trust, and understand the emotions. They've learned how to work with the many agencies and programs that will be needed to support the day-to-day activities.***

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What Children and Families Need in Health Care from Birth through Adulthood

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We found a school for Christian with gardens and animals, a small teacher-to-pupil ratio, and a director (the 80-year-old woman who started the school) who believed that self-esteem was top priority and that hands-on learning was most successful for all kids. It worked. I drove 80 miles a day in order for Christian to receive this education. The stress to our family was incredible. Where was that supportive team?

I was also very sad. I wanted to make life better for my firstborn and everything seemed bleak. Only a parent who has experienced this can image the everyday pain of putting your child to bed and wanting nothing more than to take this struggle away. I could do nothing. The lack of control is powerful.

Preadolescence brought status epilepticus, hours of seizing and the loss of speech and body function for Christian. For three years we had monthly status, so that we had to administer Valium rectally. It was either that or bring him into the hospital, and I wanted nothing to do with hospitals. It was humiliating for Christian. One night at 2 a.m. as I stood holding him on the counter when he was ending a status and had lost all speech, I asked him to draw me a picture of what he felt. He drew a circle with a face on it and then a square box around it. My interpretation was that he felt locked in a box during these times.

I took my pain and my anger and frustration and I decided to work with families to support them through their process. At first my advocacy was defensive and demanding. I was not a team player. I saw the world as them against us. That is not a productive way to develop supportive teams.

At age 18 Christian had a new team working with him - new teacher, new doctors, new therapist, new friends. The tables began to turn. His physician always talked to Christian and listened to what he wanted. For instance, Christian heard of a new medication on TV and called his neurologist to request a change; she met with us and carefully told him all the pros and cons. She let him be the leader in this decision. I listened and knew this was his decision and that I was now needing to step back. His teacher became his best friend; he developed a trusting and caring relationship that went far beyond his professional job description. I now, again, had a team who put him first and who genuinely cared about him as a man, not as a disorder or disability. Remembering this brings me to tears - I was so exhausted and so grateful for this team surrounding Christian, and it has had lifelong effect on both of us.

Provide parents with specific and yet understandable information. What is Tuberous Sclerosis or Down Syndrome or Aspergers? Parents not only need the name of the disorder, but what caused it and how it affects daily life.

Today, Christian is a 145-pound robust man. He works full-time and is respected for his skills as a prep chef. He is an avid bowler with a 180 average, often requested to be on very competitive men's leagues. He lives in his own apartment with a friend and is looking for a partner. He still has seizures, obsessive/compulsive disorder, some autism and mental retardation. It was the many doctors, nurses, therapists, teachers, family members, friends, and the perseverance of Christian himself that worked together to make this outcome possible.

Advice from the Trenches

So, after 25 years as Christian's mother what have I learned about what parents and children with disabilities need? While my experience and needs do not reflect every parent, I think some of the recommendations listed below will be helpful to professionals who work with any family such as ours:

❋ Connect parents with other parents as soon as a child is diagnosed with a disability or chronic illness. I often wished that hospitals would hire parents to be available for emotional support, and also for the connections needed upon leaving the hospital. Research supports that parents learn the most from other parents. They speak the same language, have immediate trust, and understand the emotions. They've learned how to work with the many agencies and programs that will be needed to support the day-to-day activities.

❋ Provide parents with specific and yet understandable information. What is Tuberous Sclerosis or Down Syndrome or Aspergers? Parents not only need the name of the disorder, but what caused it and how it affects daily life. This is a very touchy component because sometimes a physician provides the "worst case" scenario, and there is always a wide range of functional capacity within each label. There is also the tremendous impact of environment and internal characteristics of the child. If information is not available on site, assist the parents in finding it.

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✱ Understand the need for emotional support. Physicians, nurses and medical staff are often the only contact for parents who are in medical crisis with their children. Not only are parents exhausted physically, they need to know they are "good parents" and an occasional acknowledgment that this is hard stuff. A nurse who sat with me and listened or a doctor who let there be silence so I could gulp the lump in my throat before I had to talk, or just a touch on the shoulder, meant a lot.

✱ Give parents permission to take time for themselves and other members of the family. Parents may meet with numerous specialists in a day and be handed many different sets of care plans. This can be overwhelming and discouraging. Siblings often are the last to feel included and special because so much emphasis is placed on the person with a disability. Provide families with the information about respite care and other in-home supports, and with the encouragement that taking time is valuable for the family.

✱ Make parents an ally. I knew the most about Christian. I knew his spirit and his unspoken feelings. I wanted to be part of the decisions that were made about testing, treatment, surgery or medication. I was not educated in the same way as the professionals, but I was knowledgeable beyond the disease. Today, the many systems that work with families that have children with disabilities are encouraged to create policies that promote parents as partners. Still, I sense that there is also an ongoing education of all professionals that promotes professional distance and a hierarchy that continues to place parents lower in this ladder of knowledge. As a parent, I can respect a professional's expertise in a given field, but I will trust you for your humanity and respect for my child and me.

✱ Talk to the child/adolescent. I felt that Christian was invisible many times. As the child gets older, it is especially important to talk directly to him or her. Young people must develop a sense of control and autonomy in order to become healthy adults. Christian knew himself. His diagnosis of mental retardation did not exclude him from the ability to give meaningful information.

> Parenting a child with a disability has provided many opportunities and challenges, with most of the hardships coming from the lack of respect, care, and value provided the more vulnerable and interdependent in our culture.

✱ Provide normal development information to parents and children. During the adolescent years, talk about sexuality, peer support, healthy relationships, vocational and education aspirations. This will also help parents move beyond the disability or chronic illness and begin to think about all the possibilities that they think of with their other children. I was so afraid that Christian would experience failure at everything that I wanted to keep him next to me so I could protect and defend and support everything. I forgot that a healthy person needs failure and triumphs, aloneness and togetherness, choices and most of all a sense of self, separate from mom. Helping parents find safety nets so that they can step back and watch their children survive and thrive is a huge gift.

✱ Check for mental health! Many children and youth struggle with being different and having a disability. Many times they are depressed, confused, isolated and bullied because of the disability. Undiagnosed emotional or psychological needs prevent them from planning for the future, and dreaming dreams of having their own job and family and friends. Parents may know that the child is depressed, but may think that it is understandable given the disability and not pursue any support. Often support does not mean psychotherapy or psychotropic drugs, but a friend or mentor to talk to or opportunities to feel they belong, have a chance to give back, and explore and develop their own goals.

✱ Celebrate the gains. Many children and youth meet with specialists related to their disability or chronic illness and do not experience a pediatrician or family practice doctor who celebrates their gains in school or home. Tell parents how wonderful their children are and how far they have come. Christian worked harder than any of my other children to learn how to talk, cut with scissors, take a bus, have a job, and speak for himself. Those are celebration events.

Parenting a child with a disability has provided many opportunities and challenges, with most of the hardships coming from the lack of respect, care, and value provided the more vulnerable and interdependent in our culture. Christian has taught me more about determination, resilience, honesty, and living in the moment than I will ever teach him. And I thank those people along the way who encouraged and supported us.

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UNIVERSITY OF MAINE

Center for Community Inclusion, UAP Maine's Center for Interdisciplinary Education, Research and Community Service in Disability Studies

Project Specialist Positions Available

The University of Maine's Center for Community Inclusion, UAP, has a number of positions available, including two (2) full time Education Specialists to join the Center's Inclusive Education team; two (2) Early Care and Education Specialists, a Mental Health Specialist and a Health Care Specialist to join the Center's Early Childhood team.

Responsibilities:
The responsibilities of the Specialists include providing community education, technical assistance, materials development/ dissemination and assisting with research and evaluation activities to support the high quality and meaningful inclusive early care and education of young children with disabilities in early care environments and childcare settings and students with disabilities in school.

Responsibilities include planning and conducting workshops, seminars and providing onsite technical assistance to early care and child care providers, schools and related services throughout the state. Must be able to work a flexible schedule including occasional weekends and evenings, as needed. Statewide travel, normally requiring a valid driver's license, is required.

Knowledge and skill qualifications:
Master's Degree in education, special education, early childhood special education, or related field is preferred. A combination of four years of education and experience, equivalent to a Bachelor's degree, and demonstrated experience working in inclusive early care and childcare settings and schools are required. The Mental Health Specialist requires a Master's degree and substantial experience providing positive behavioral supports to young children with serious behavior and social/emotional challenges and their families; candidates with psychology, social work or early childhood special education certification/licensure are preferred. The Health Care Specialist requires a Bachelor's degree in nursing, state licensure as a RN and substantial experience; a master's degree in nursing and several years' experience in pediatric nursing preferred. These positions require excellent communication and organizational skills and the ability to work collaboratively with other faculty/staff in the provision of technical assistance, materials development and community education. Preference will be given to those with professional experience in continuing education and/or technical assistance. Appropriate background checks will be required.

Salary Range:
These are full-time, fiscal year appointments contingent upon external funding. Annual salary based upon education and experience, with full University benefits.

Review of applications will begin November 27, 2000 and will continue until the positions are filled.

Send cover letter specifying position(s) for which you are applying, curriculum vitae, proof of licensure, as required above, three letters of recommendation, and transcripts to:

Pamela Flood or Linda Labas, Co-Chairs, Project Specialist Search Committee
Center for Community Inclusion, UAP
University of Maine
5717 Corbett Hall
Orono, Maine 04469-5717

For information about the Center please visit: http://www.ume.maine.edu/~cci/

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Re-thinking Guardianship

BY DOHN HOYLE and KATHLEEN HARRIS

Guardianship, at one time seen as a benign way to "protect" people with disabilities, is now seen as an intrusion into a person's basic civil and human rights and a legal process to be avoided. Guardianship was originally used to handle and control property and property rights for individuals considered incompetent (or in the language of most early statutes -- "imbeciles, idiots, feeble-minded, insane and cretins"; "gamblers and ner-do-wells" were sometimes also included). Guardianship of the Person was added as an afterthought to the duties of a Guardian of the Estate.

Change has come about as part of questions that have been raised since the 1970's about the way our society in general views and treats individuals with disabilities. It was in the '70's that the first class-action suits were filed regarding the deplorable conditions in institutions. Such legal actions highlighted the general abuse of the rights of individuals with disabilities. Courts all over the country began ordering community-based services and concerning themselves with the enhancement of dignity and the protection of basic civil and human rights of individuals with disabilities. New laws were passed in recognition of the need to integrate citizens with disabilities into our communities, including the Developmental Disabilities Assistance and Bill of Rights Act (DD Act)[1], the Individuals with Disabilities Act (IDEA)[2], and the Americans with Disabilities Act (ADA)[3], the most significant civil rights legislation ever passed for people with disabilities. All these laws have promoted inclusion of individuals with disabilities into their own communities and brought new awareness of the abilities and contributions of people with disabilities to our society.

Guardianship laws began to change as well. Many states introduced a list of due process protections for people who became subject to guardianship petitions such as the right to hearing, lawyers, and independent evaluations. Most revised laws also express a clear preference for partial guardianships for limited decision-making power rather than full guardianship over all possible life decisions.

Even with these changes in the law, individuals with disabilities still suffer from a lack of due process because of paternalistic attitude and duplicities in guardianship proceedings that confront persons with cognitive disabilities or those with difficulty in communicating. In fact, persons alleged to have committed criminal acts have their due process rights far more zealously guarded prior to being deprived of their right to life, liberty or the pursuit of happiness. Before they lose their money or are incarcerated, (in sometimes remarkably similar types of institutions), they are afforded real due process protections.

While these legislative changes have been taking place, person-centered planning has become the planning process for people with disabilities. In Michigan, it has even become law.[4] The person-centered planning process is defined generally as a process of planning for and supporting an individual that honors the individual's preferences, choices and abilities. The person-centered planning process assumes that all people have preferences, regardless of their level of disability. Through this process, the person's preferences are determined by any method possible. In some cases, observations of the individual's behavior by those closest to them are used to determine preferences. Such preferences are then honored as long as they are not harmful to the individual. This process of determining preferences and choices enhances the dignity and self-determination of individuals and is far more reliable than having a court-appointed, single person to make all decisions with or without the input of the individual with a disability.

> Education of those recommending guardianship is needed as many professionals and lay people, as well as court personnel, believe guardianship is the only way to resolve many issues that can be handled through less intrusive methods. We need to stop applying a legal solution to personal issues that can be handled through a person-centered process.

As the law established person-centered planning and individuals' rights to make decisions about their treatment options, Self-Determination Initiatives began developing. The Robert Wood Johnson Foundation provided funding to 19 states for Self-Determination Initiatives demonstration projects. The projects sprung from reforms that question the almost total control public funders and providers have over the life choices of individuals with disabilities and their families. In that system, funds and decisions are allocated to providers. Individuals with disabilities and their families have little or no say about which providers are to supply services or what those services should be. Changing this

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imbalance of power and control is the goal of self-determination. Decision-making by the individual is key to this effort. Obviously, appointing a guardian to make decisions for the individual can defeat this process. However, asserting that each individual should make their own decisions doesn't mean that each individual doesn't need help, assistance and support.

The Iowa Supreme Court has recognized that outside supports for an individual may negate the need for guardianship. In making a determination as to whether a guardianship should be established . . . the court must consider the availability of third party assistance to meet a . . . proposed ward's need for such necessities . . .[5]

Tom Nerney, Executive Director of the Center for Self-Determination has stated:

"We have to reject the very idea of incompetence. We need to replace it with the idea of 'assisted competence.' This will include a range of supports that will enable individuals with cognitive disabilities to receive assistance in decision-making that will preserve their rights . . ."[6]

Thus, just as supports have evolved since the '70's to assist individuals with disabilities to participate in education, employment, housing and other community opportunities, supports are now evolving to assist people in decision-making. "Assisted living" has replaced institution living, and "supported employment" has provided more job opportunities. "Assisted competence" is now continuing the evolution that enables people with disabilities the dignity and freedom to develop and participate in the lives they want and choose.

Stanley S. Herr, Professor of Law, University of Maryland School of Law has studied guardianship laws over the world. He states:

"A number of countries have adopted new legislation in recent years to minimize the use of guardianship, to impose only its least restrictive alternatives, and to introduce other innovations . . . The imposition of guardianship posed important ethical, legal and practical problems for the disability rights community . . . The ethical questions involve ideas of paternalism, liberty, prevention of harm and exploitation, beneficence, and the power relationships between guardian and ward. Finding better answers will implicate vital principles of self-determination, including freedom, authority, support and responsibility."[7]

Thus, support systems in most states are exploring alternative means to guardianship and ways to restrict the effects of the imposition of guardianship on the choices of individuals with disabilities.

These efforts have resulted in the development of many alternative methods to handle decision-making that assist individuals with disabilities and their advocates. For instance, the use of durable powers of attorney are used in order to designate a person to discuss and make decisions about medical decisions, living situations, confidentiality issues and other areas of concern. In this way, family members or others who have always assisted the individual in making such decisions can continue to do so without filing a petition to become guardian and actually take away the right of the individual to make such decisions. The power of attorney allows the individual to give that power to someone, and they can also take away that power if they become unhappy with the decisions being made. Many state laws will allow for such powers of attorney and also recognize that the level of informed consent needed to execute such a document is lower than that needed for other legal arrangements under law. As an example, in Michigan the standard for executing a medical power of attorney is that the individual must be "of sound mind," which is the same standard as seen in the realm of Michigan wills and testaments. In order to execute a will, "average mental capacity at the time of the execution of the will is not necessary to its validity. A lesser degree of mind or capacity is requisite to execute a will than to make a contract covering the same subject matter."[8]

Another example of devising alternatives is the concern about who will take care of the individual's money if they are totally unable to handle it themselves. The majority of people with developmental disabilities are recipients of Supplemental Security Income (SSI). For these and other governmental benefits, the government will designate a "payee" -- someone to receive and disburse the money for the individual if the person is determined incapable of managing the funds him or herself. A guardian of the estate or conservator would be a duplication of this function. If a substantial amount of money comes into the individual's life, there are trust documents that can be drafted that can protect the governmental benefits and still use the funds to provide an enhanced life for the individual. A trustee or co-trustees can be designated to distribute the funds and see that the individual's needs and desires are met. Such a trust can specify that someone visit the person and assure that the individual is satisfied with his or her living situation and support systems. This is more than the imposition of a guardian or conservator can do for an individual and gives more peace of mind to parents who worry about what will happen to their child when they are gone. A knowledgeable attorney should be consulted about these trust documents.

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Re-thinking Guardianship

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The above are major alternatives to guardianship, and there are many more that can be devised. There are as many alternatives as there are issues. Education of those recommending guardianship is needed as many professionals and lay people, as well as court personnel believe guardianship is the only way to resolve many issues that can be handled through less intrusive methods. We need to stop applying a legal solution to personal issues that can be handled through a person-centered process.

Putting an end to the systematic removal of rights and the concomitant removal of protections for people with disabilities needs to be a priority. This would mean a different way of doing business. Those who care about an individual with a disability and those who make their living because of individuals with disabilities, have an obligation to discover what people like and don't like, what their desires and preferences are. We should employ the many alternatives which currently allow people to avoid guardianship altogether. Ultimately, we can use the framework of person-centered planning and self-determination to obtain the optimum choice making. We can assure individuals with disabilities, including those with cognitive disabilities and disabilities that impair their communication, access to life, liberty and pursuit of happiness. Plus, we will have eliminated an unnecessary barrier to individuals' opportunity to seek their piece of the American dream.

Dohn Hoyle is President and CEO of the Assoiation for Community Advocacy in Ann Arbor, Michigan. He has been active for 30 years with numerous advocacy organizations on behalf of individuals with disabilities and has been a long-time proponent of alternatives to guardianship. Kathleen Harris is an attorney and disability advocate in Clarkston, Michigan. Kathleen has represented individuals with disabilities in all areas of disability law, including guardianship.

For further information, or to contact Dohn or Kathleen, call the Association for Community Advocacy at 735-662-1256.

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[1] 42 U.S.C. § 6012

[2] 20 U.S.C. §1400 et seq

[3] 42 U.S.C. 12101 et seq

[4] MCL 330.1712; MSA 14.800 (712)

[5] In the Matter of Hedin, Iowa Supreme Court, (1995)

[6] Common Sense, Issue 6 - 1999; a publication of the National Program Office on Self-Determination, University of New Hampshire, Insititute on Disability, funded by the Robert Wood Johnson Foundation

[7] Id.

[8] Bean v. Bean, 144 Mich 599, 108 NW 369 (1906)

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Pediatric Family Liaison Project

BY SALLY J. DEITZ, Ph.D.

Families of young children with significant disabilities often struggle through a complex system of medical establishments and procedures, experiencing frustration at their efforts to gain meaningful information and to advocate successfully for their child. Confusion is compounded when a family does not speak the language of the medical staff, or has traveled to get the medical care, leaving a support of family and friends behind. Here we describe an innovative solution to these challenges that is being used by ORBIS International on their flying DC-10 eye hospital. This flying eye hospital travels worldwide approximately ten weeks per year. Services are devoted to pediatric eye surgery in developing countries, often serving children with medical or physical conditions other than visual impairment.

As professionals in the field of childhood disabilities are aware, visual impairment in various forms occurs frequently and rarely occurs in isolation. Not only are children with visual impairment often diagnosed with other health conditions, but children with various levels of disability are often found to have visual impairments as well. Having the best possible eye health and refractive error correction assists every child to learn better and to function more independently. This article describes an innovative international effort to not only assist families with the process of surgery for their children, but also to teach them to become advocates for their child as they negotiate medical situations in the future.

ORBIS International is a nonaligned, nonprofit, humanitarian organization dedicated to saving the sight of both children and adults. They do this through education and hands-on training for ophthalmologists and a wide spectrum of other medical personnel. ORBIS has conducted training programs on board its DC-10 flying eye hospital for 18 years, and has sponsored hospital-based programs in local hospitals around the world.

During these programs, visiting faculty demonstrate techniques for treating eye diseases that are of greatest concern to their local colleagues. During the past two years, ORBIS has also undertaken the establishment of several long-term, country-based programs in order to focus its efforts in regions where there is a high incidence of avoidable blindness and a willingness to develop quality eye care systems. There are now ORBIS country offices in India, Bangladesh, China, and Ethiopia. Within the next two years, a country program office will open in Vietnam.

ORBIS staff on the DC-10 hospital have become increasingly aware of the need to facilitate the surgical experience for families. In discussion, the need for a Pediatric Family Liaison became clear; a person to mediate communication between children, families, and ORBIS staff during the weeks in which pediatric surgeries take place on the ORBIS DC-10. This new role assists the plane staff to meet the needs of families, engages the families and their children throughout the waiting periods of each surgical day, and eases the stress of the experience for all concerned.

The Pediatric Liaison decreases the stress for the families by doing the following:

❇ Staying with families in the waiting area and the Recovery Room;
❇ Engaging children and families with toys and materials throughout the waiting pre-operative time;
❇ Modeling in asking questions about the child's condition, treatment, and prognosis;
❇ Coaching family members through the pre- and post-operative period to assure them of the safety of their child and routine nature of their child's reactions during this time;
❇ Engaging the translators whenever needed to answer each family's questions;
❇ Assuring that family members take breaks for lunch, water, rest, and refreshment by providing assistance in the family member's absence
❇ Visiting the recovery room regularly to report back to the family member how the surgery is progressing; and
❇ Creating an atmosphere of comfort and calm in the waiting area, making it child and family friendly.

Children are selected for surgery during "pediatric weeks." These weeks typically include cases of strabismus, glaucoma, traumatic cataracts, and retinal detachment. A typical pediatric week comprises four to six surgeries per day, with children returning to the local cooperating hospital for post-surgical care. Often these children travel great distances from rural areas for the

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Pediatric Family Liaison Project

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surgery, and many times they and their families have waited a few years for this opportunity to be treated. For many of these families, this medical experience is the first time they have been exposed to a hospital setting, anesthesia, or surgery.

> The purpose of the ORBIS DC-10 project is not only to make the surgical procedure easier for the entire family, but it is also to model for them the advocacy that they will need throughout their children's lives as they negotiate continued medical treatment.

The process of receiving eye surgery on the DC-10 is highly structured, and for the families, the day of surgery poses unique stresses. When children arrive on the plane for the designated surgery, each with one family member, they spend much of the day in the waiting area. This is also the only room on the plane that does not receive live transmission of surgeries as they are performed. Because the children have been prepared for surgery, they have not had food or water since the previous night, and will not have it until after the surgery. Often the wait for the day's surgery can last until mid-afternoon.

Thus, each family member is faced with a confused, frightened, and hungry child, isolation from other family members, language barriers with everyone but the medical translators on each team, and uncertainty about what to expect during the child's surgical procedure and afterwards. Prior to establishment of the Family Liaison role, family members would often leave the designated waiting area, seek a translator to answer their questions, or observe their child's surgery on one of the monitors. When this happened, it created confusion and miscommunication between families and airplane staff, all of whom were already managing a highly orchestrated medical schedule in a small space.

Under the best of circumstances a child's surgery is difficult for all concerned. Through this project ORBIS seeks to alleviate the surgical pre- and post-operative stress for all families involved, and also to assure smooth flow of communication amongst medical staff, children, and caregivers.

While the purpose of the project is not only to make the experience on the ORBIS DC-10 easier for families, it is also to model for them the advocacy that they will need throughout their children's lives as they negotiate continued medical treatment. ORBIS recognizes that although this medical intervention may be a part of each family's life for a short time, the families are preparing for a lifetime of advocacy for which they will use negotiating skills.

Questions about the work of ORBIS Intl. may be directed to Sally Dietz at (sally@ny.orbis.org) or call Dr. Dietz at (212) 244-2525, ext. 211.

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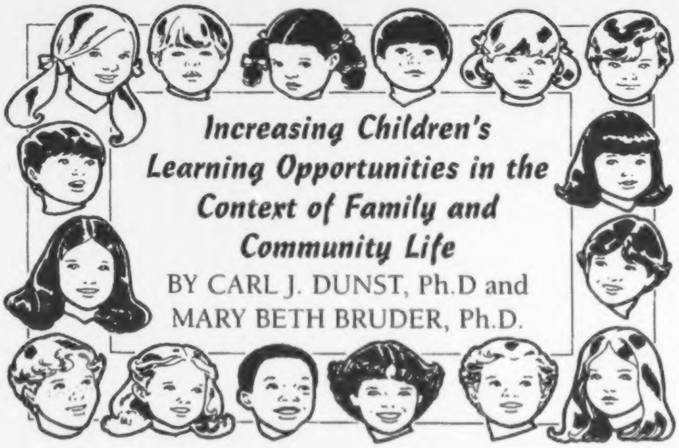

Increasing Children's Learning Opportunities in the Context of Family and Community Life

BY CARL J. DUNST, Ph.D and MARY BETH BRUDER, Ph.D.

The Children's Learning Opportunities Early Childhood Research Institute is a 5-year initiative funded by the U.S. Department of Education, Office of Special Education Programs. Institute staff are identifying, developing, and evaluating ways of using family and community life as sources of learning opportunities for infants, toddlers, and preschoolers with or at-risk for delays in their development. Institute staff are especially interested in identifying everyday experiences that provide children learning opportunities which strengthen child capabilities and promote new competencies.

The value and importance of learning in different early childhood programs has been well documented. Our main focus, therefore, is children's learning that happens as part of daily living, family rituals, family and community celebrations, special occasions and events, and just about anything and everything else that a child experiences intentionally or incidentally as part of family and community life.

Family life includes a mix of people and places. These people and places provide a child a variety of learning opportunities like eating during meal times, splashing water during bath time, listening to adults share stories, and learning greeting skills at family get-togethers. Community life also includes a mix or people and places that provide children many different kinds of learning opportunities. These include the people and things experienced on neighborhood walks, playing at a park or in the woods, children's festivals and fairs, nature centers and farms, and so forth.

Research Studies

Institute staff are conducting different kinds of studies to learn about sources of children's learning activities, and the kinds of practices associated with child, parent, and family benefits. This article highlights the kind of studies that we are doing.

Natural Surveys

Two national surveys of nearly 330 parents were conducted in 48 states, Puerto Rico, and Yap in Micronesia. One survey looked at family life as sources of children's learning opportunities, and the other looked at community life as sources of learning opportunities for children. The surveys were completed by parents and other caregivers of children in early intervention programs, early childhood special education programs, Early Head Start, and other early childhood programs (e.g. Even Start, Parents as Teachers).

Findings from both surveys show that family life is made up of 11 different categories of learning opportunities, and that community life is also made up of 11 different categories of learning activities. Learning opportunities available to children in family life includes such things as parenting routines (e.g., child's bedtime), child routines (e.g., brushing teeth), literary activities (e.g., telling child stories), parent/child play (e.g., lap games), and socialization activities (e.g., family gatherings). Community life providing children learning opportunities includes such things as family routines (e.g., doing errands), play activities (e.g., playgrounds), recreation and sports activities (e.g., swimming), and art and entertainment activities (e.g., children's theater).

Descriptive Studies

To learn about the make-up of family and community life of young children, we conducted in-depth descriptive studies of more than 200 families of children with disabilities or delays, children at-risk for socioeconomic reasons, and children not-at-risk for any reason. The children and families were from Alaska, California, Connecticut, Hawaii, North Carolina, New Mexico, and Wisconsin. The participants were diverse in terms of their cultural, ethnic, and socioeconomic backgrounds; place of residence (urban, rural, suburban); and child age and developmental status. Research staff visited the families up to 12 times over a 6-month period to interview the parents about their family and community lives, observe the children in different family and community learning activities, and to gather information about the variety of learning experiences, opportunities, events, and so forth that happened for the children.

Findings show that children participate in many different social and physical settings as part of their family and community lives. These different settings in turn provide many different kinds of learning opportunities.

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Children, on average, participate in some 150 different kinds of social and physical settings as part of family and community life. These settings in turn provide more than 200 different kinds of learning opportunities.

Intervention Studies

Institute staff conducted intervention studies with nearly 75 children with disabilities or delays and their families to evaluate four procedures for using family and community life as sources of children's learning opportunities. The studies were done in California, Connecticut, Hawaii, North Carolina, New Mexico, and Wisconsin with families from diverse cultural, ethnic, and socioeconomic backgrounds. The four procedures included: (1) a schedule for reminding parents to involve their children in learning activities, (2) a matrix for focusing on the behaviors a child would do in different learning activities, (3) parent responsiveness to desired child behavior as a teaching method, and (4) family and community activities as learning opportunities on a child's IFSP or IEP. Findings indicate that parents prefer interventions that are easy to do, fit into their daily lives, and emphasize children doing and learning things that help them be part of family and community life.

We are continuing to conduct comparative studies and practice studies in our quest to document the everyday learning opportunities available to promote children's abilities.

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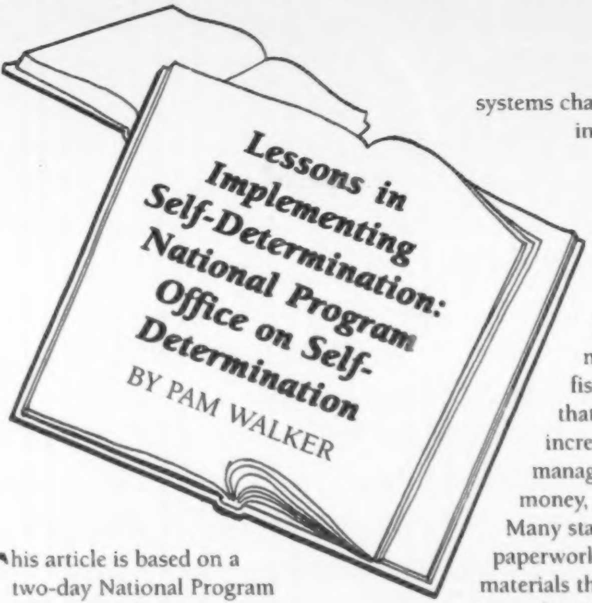

Lessons in Implementing Self-Determination: National Program Office on Self-Determination

BY PAM WALKER

This article is based on a two-day National Program Office on Self-Determination Annual Project Directors' Meeting that took place in Fall 1999. Participants included staff of the National Program Office, project directors and other representatives from grantee states; representatives from technical assistance states; representatives from People First of Tennessee, The Self-Advocacy Association of New York State, Inc., Speaking for Ourselves, Pennsylvania, and the National Parent Network on Disabilities (NPND); and representatives of the Human Services Research Institute (HSRI) and the Center for Outcome Analysis (COA). The article highlights themes of the discussion, which are based on nearly 3 years of work implementing self-determination.

Recognition that systems change is complex and takes a long time

The initial Robert Wood Johnson Foundation grants to 19 states were for 3 years. During this time, as a result of project efforts, many individuals with disabilities have gained significant control over their lives, and have experienced many positive life changes as a result. For example, in one state, it was reported that, "For the first time, consumers and family members really came to the table as equal partners."

At the same time, the experience across all states is that 3 years was just time enough to make the initial steps toward systems change. For example, in many of the states, even those already having individual budgets, it has taken most of the 3 years to set up mechanisms, such as fiscal intermediaries, that will give people increased options for managing their own money, if they so choose. Many states still have paperwork and informational materials that are not accessible to people with disabilities. Some states are beginning, together with self-advocates, to develop more consumer-friendly information and resources. States are struggling with the challenges of running "dual" systems of services as they make the transition to individualized supports based on self-determination principles. In addition, within many service systems, individuals and families often still have very limited real choice of service providers.

Overall, there is recognition that the move toward self-determination will be difficult for many agencies, as it will involve having significantly less power and control. As one participant put it, "We need to work on breaking down programs. The people I know who are leading self-determined lives are not in programs. People in programs don't get a life."

Thus, overall, while there have been many significant changes initiated as a result of the self-determination projects, there are also still many problems within the service system, and many hardships for people with disabilities in dealing with the system. As a self-advocate commented, "Right now, the way the system is, you still have to fight so hard to get what you want. Self-advocates have been talking about self-determination issues for years, but there are still a lot of people who don't want to listen, who think in old ways, and are used to having control." Participants stressed the importance of those without disabilities taking more time to really listen to people with disabilities.

Within the projects, people have strategized regarding how best to promote agency change that will be conducive to opportunities for self-determination. People in project states have worked to help build the principles of self-determination into agencies. In doing so, some have felt it has been best to begin working with one or a small number of agencies to identify and/or develop success stories. Then, these agencies, and success stories, can be used to assist other agencies to change. In working toward agency change, it is critical to acknowledge the efforts that are currently being made by agency staff: As one state project director commented, "Many people are moving along. It is important to recognize these steps." While it is crucial that agency administrators adopt a vision of self-determination, it is equally important for others in the agency to do so. This includes people in key gatekeeping roles, such as case managers, and it includes direct support staff. In particular, participants stressed the ongoing need to search for ways to adequately compensate and validate direct support staff.
Overall, there is recognition that the move toward self-determination will be difficult for many agencies, as it will involve having significantly less power and control, as well as a shift in roles, moving beyond providing programs for people. As one participant put it, "We need to work on breaking down programs. The people I know who are leading self-determined lives are not in programs. People in programs don't get a life." While these changes are significant for agencies, there is evidence that it is beginning to happen in some of the project states.

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During the course of systems change, it is important to have a variety of ways to keep focused on the values and mission. Without this, according to a state administrator, "at any given moment, people are likely to revert back to the old way of doing business, particularly during times of stress." Even with this, participants agreed that systems change will take a long time, perhaps 5-10 years and more. At the same time, they agreed about the need for a sense of urgency in efforts to promote self-determination.

Importance of defining self-determination broadly

People in the project states have defined self-determination broadly, "based on the individual." Definitions include a focus on assisting people to have the "capacity to determine and direct their lives," "having the power to direct your own support," "having information and resources," an "array of support options," and "responsibility." Emphasis is placed on being inclusive, rather than exclusive. "We have to be careful not to foster the idea of who is in, and who is out-it is for everyone."

People have learned to think of self-determination for everyone-not just people with disabilities. For example, the project director from one state reflected, "Experience has taught that those regions that have been the most successful are those that take a very broad view, looking at self-determination for all people, including families, agency staff, direct support providers, and so on." Another person added, "The self in self-determination is all individuals."

Part of trying to explain what self-determination is involves explaining what is different about it. For instance, in one state they are emphasizing to people that "self-determination is not just a person-centered plan, but a person-centered way of life." Also, people are concerned about being clear that it involves radical systems change, "not just tweaking the system." Finally, participants agree on the need to be clear that "it is not a program, or a checkbook; it is also not about having to make the right choice right now because this is your only chance."

Even though self-determination may be defined broadly, this does not mean that everyone has access to it. Many states began with pilot projects for a limited number of people, or began with a focus on a particular group of people, such as those on the waiting list for services. Even in states where self-determination is available statewide, this does not mean everyone has access. For instance, participants found that, initially, many people who first expressed interest in self-determination were those who are strong advocates themselves, or who have strong advocates in their lives. A challenge will be to expand access to self-determination, particularly to those in congregate facilities.

Focus on incorporating self-determination principles into the system, but guard against self-determination becoming institutionalized or systematized

Participants expressed a desire to build self-determination principles into agency policies and practices, waivers, and other aspects of the system; but, at the same time, they recognize that self-determination is not a part of the system. Participants expressed concern that some people have a misconception of self-determination as a service or program. As one project director explained, "We've gotten away from using the term self-determination because of some of the misconceptions about it as a service or program-and we've focused more on values that we want for all people." Another person emphasized that talking about "pilot projects," or "special initiatives," also tends to promote the idea of a program, in which some people are in and some are out. "The only way that we were successful in having people get out of the project mentality was by saying there are no longer any special initiatives. There are no longer the haves and the have nots-self-determination is just the way of doing things." Finally, people spoke against systematizing self-determination. "We need to be cautious about institutionalizing anything again; when we do that, we do that with the assumption that we are 'there' again and have the answer." Another person added, "The reason self-determination works is because it is not part of the system. While state agencies want to support self-determination, it won't work if it becomes part of the system."

Working in coalition or partnership demands that those who are used to having power and control give this up. As a result of states' self-determination projects, there are the beginnings of new and broader coalitions in states, with increasing inclusion of people with disabilities. Participants specified that people with disabilities and families must be central to these coalitions and partnerships.

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Recognition of the complexity of control/power issues

The experience in the self-determination projects is that, for some individuals, there have been major shifts in control over money, along with a high degree of satisfaction. Such shifts in control of money are an important component of self-determination. However, experience has also taught that this alone is not sufficient. One panelist emphasized the importance of recognizing that power is often, though not exclusively, linked with money. "Power lies in other places, too, and is not just related to money." Another person commented, "Simply taking the money from the service system and dropping it into the mix of people around the person doesn't resolve all the issues about power." In addition, it is recognized that people need support in assuming control over money and other decisions. "We've seen some situations where people have the money, but don't have a circle around them-they are kind of abandoned with the money." A self-advocate added, "Some people who have lived in institutions all their lives may not know how to go about making decisions for themselves, so we need to make sure they get support in figuring things out." Further, participants addressed the need to respect people's decisions. One person commented, "I need to be able to make my own choices, even though there might be risks. I need to have that experience of choosing, even if it's not what you think would be best."

Recognition of the role of Medicaid, Supplemental Security Income (SSI), and other technical issues. Many participants spoke to the importance of addressing technical barriers to self-determination posed by Medicaid, SSI, and other regulations. Some of these include:

- use of Medicaid waiver funds to pay for room and board (e.g., this is being done in some places but not in others)
- SSI in relation to housing and employment
- Personal Care Attendant (PCA) services and people labeled with cognitive disabilities operation of fiscal intermediaries

People discussed the need to identify and share success stories about resolution of these and other issues. States have begun to deal with these issues, but now there is need to share these success stories and strategies within states, as well as between states.

While some participants feel that Medicaid is a major barrier to self-determination, others do not see it as a major barrier. Overall, two issues related to Medicaid were emphasized. First is the need for it to be seen as a funding stream, not a program. "If Medicaid is going to work in terms of individually tailored services, it has to be seen as a funding stream." The second issue is how Medicaid is applied. "More than anything else, in terms of Medicaid, is that it is applied very differently in different situations." People proposed that there be dialogue with the Health Care Financing Administration (HCFA) about these issues. As a part of this dialogue, it is important to identify examples of how and where Medicaid issues are being resolved in ways that are flexible and promote self-determination. In particular, also, there is need to identify positive examples of how fiscal intermediaries are working in relation to guidelines for spending money, tracking money, and so on. It was also pointed out that it is important to recognize the flexibility that exists within Medicaid, and to simultaneously identify and address other problems in the system beside Medicaid. For example, Medicaid includes provision for choice of vendored services. "The problem with the system is that there aren't any choices, so we need to focus on expanding options."

People raised a number of concerns related to Supplemental Security Income, as well. SSI is a major issue in relation to housing. For example, one person commented on being penalized for saving for a down payment for a home. Also, people talked about feeling threatened about employment and loss of benefits. Some states are beginning to work with the Social Security Administration (SSA) to resolve these issues; it was suggested that, as for Medicaid issues, it is important to identify positive examples, and to have further dialogue with the SSA about this.

Need to build coalitions/partnerships

As a result of the projects, there are the beginnings of new and broader coalitions in states, with increasing inclusion of people with disabilities. Many participants emphasized the need to continue building diverse coalitions and partnerships. Working in coalition or partnership demands that those who are used to having power and control give this up. Participants specified that people with disabilities and families must be central to these coalitions or partnerships. Self-advocates need to be included in all aspects of this work for self-determination, including the most technical. As one self-advocate put it, "We can help you to make the issues clear, because we live with them." Recognition was given to the critical role that self-advocates have been and are playing in systems change. For example, self-advocates have played a critical role in institution closure in Tennessee and Pennsylvania; in New York, recently, it was self-advocates who demanded increased opportunities for self-determination from the Commissioner. At the same time, participants pointed out that it is crucial that there be support (financial resources, access, accommodation) for involvement of self-advocates.

Need for a sense of urgency

Through the 2-day meeting, people repeatedly mentioned the need for a sense of urgency in promoting self-

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determination and the accompanying systems change. As one person put it, "We need to quicken the pace as much as possible, and bring as many different stakeholders along as possible." Participants felt that there is need to quickly build a critical mass or groundswell of people who support self-determination, so that it will not be jeopardized by oppositional forces. It was acknowledged that "there are still many people out there who are opposed to this, and who don't believe in the principles of self-determination." Some participants cautioned about going too quickly, and not being inclusive. However, consensus was that there is need to work so that people see real change within their lifetimes.

This document was produced at the request of the National Program Office on Self-Determination. For further information, contact:

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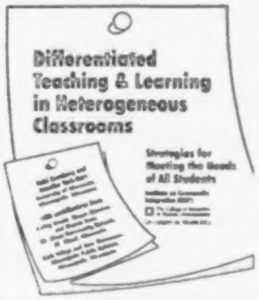
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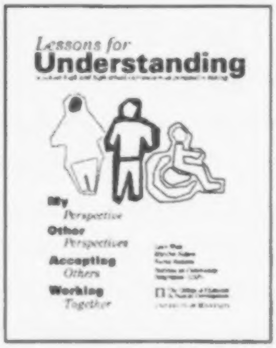
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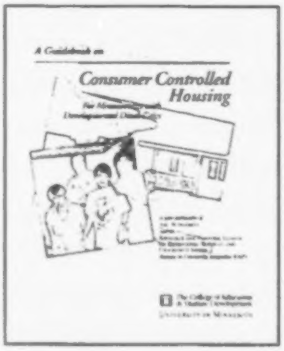
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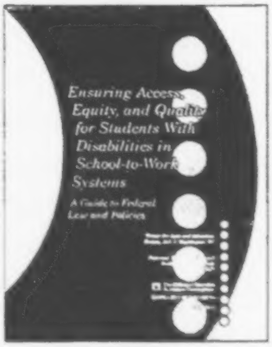
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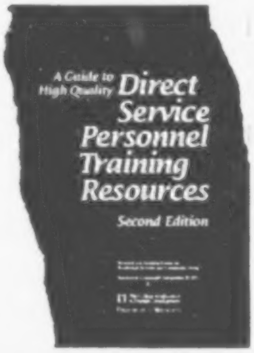
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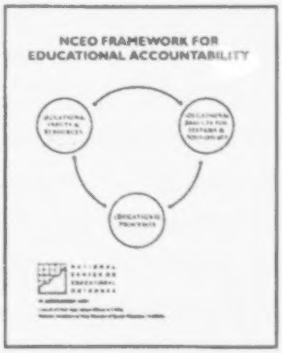
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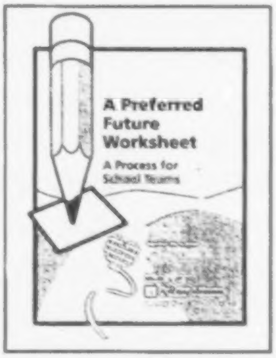
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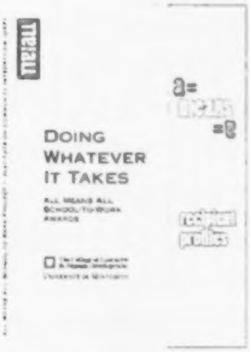
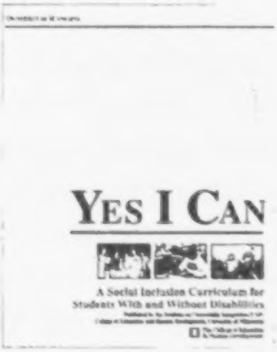

DOING WHATEVER IT TAKES

Weaving Inclusion
Seven Threads to Strengthen School Membership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Reflective Practice
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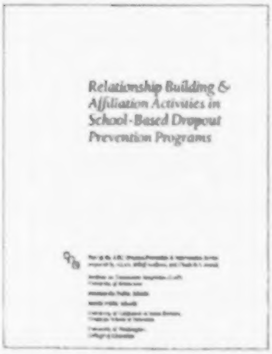
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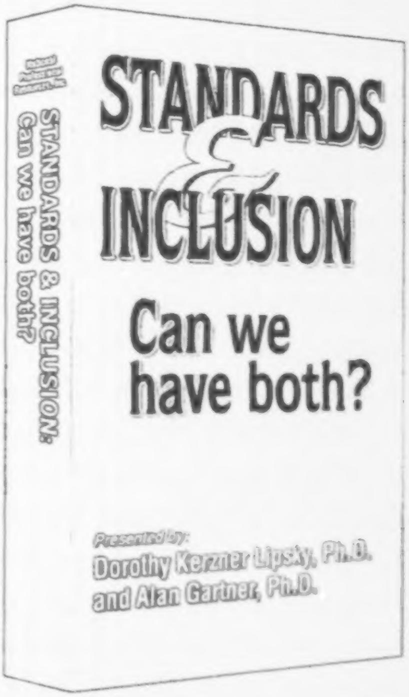

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About the Authors:

Dorothy Kerzner Lipsky is Director of the National Center on Educational Restructuring and Inclusion, and Alan Gartner is Dean for Research. Both are at The Graduate School and University Center, The City University of New York.

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TASH NEWSLETTER

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It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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2000 CONFERENCE HIGHLIGHTS

"As you go about working to put the values of human dignity, social justice, peace and compassion into practice, and calling upon society to live up to these same ideals, I am confident that you will continue to make a world of difference in the lives of individuals and families around the globe. You, as an organization, have been doing so for twenty-five years."

From the keynote address
of Dr. Oscar Arias

ALSO INSIDE:
2001 Call for Presentations; TASH Public Policy/Legislative Update; and Call for Nominations for JASH Editor

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

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Stretching the boundaries of what is possible;

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Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

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Supporting research and disseminating knowledge and information;

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Promoting inclusive education;

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Supporting progressive legislation and litigation; and,

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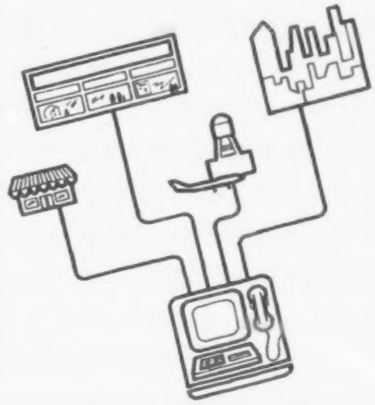

Join the TASH Update E-mail Listserve!

This is a forum for TASH members, friends and supporters to discuss the latest issues affecting people with disabilities. The listserve provides members and other interested persons with an opportunity to identify and connect with others who share particular interests, expertise and experiences.

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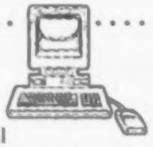

WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2001 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
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From the Executive Director
BY NANCY WEISS

TASH's annual conference is not only an opportunity to reconnect with old friends, learn new things, share your ideas, and network with people who share your passions, it is also the setting for the TASH Executive Board's annual meeting. The Executive Board meets four times a year, twice by teleconference (Spring and Fall) and twice, in-person (Summer and Winter). Here are some recent Board activities which may be of interest.

New officers were elected. Donna Gilles is TASH's new President; Jacki Anderson is our new Vice President; Jorge Pineda will serve as Treasurer; Barbara Ransom as Secretary and Doug Biklen will serve as Chair of the Executive Committee.

New Director of Governmental Affairs. Jamie Ruppmann was introduced to the Board as the newly hired Director of Governmental Relations. Jamie makes a wonderful addition to the TASH staff and you'll be hearing lots from her. Read more about her on page 5 of this *Newsletter*.

The Board agreed to continue to work on these priorities for this year:

- Collaborate/build support and connections with general educators and general ed. organizations;
- Collaborate/build support and connections with other disability and social justice organizations;
- Create and maintain a presence on Capitol Hill, build relationships with legislators and staff;
- Work toward closing institutions and other segregated living and work settings and work toward assuring that people with disabilities have meaningful employment and living opportunities;
- Promote inclusion within higher education;
- Promote enforcement of IDEA;
- Promote passage of MiCASSA;
- Fiscal development;
- Increase membership;
- Develop working relationships with committees to assure that they have the support needed to accomplish tasks; and,
- Improve relationships with and support of chapters.

Time was spent at the conference in Miami Beach capturing the activities of both the chapters and the committees in working toward these priorities. The Board began planning for a TASH leadership day that will be held next year on the Wednesday prior to the conference. Committee chairs, Chapter officers, staff, Board members and other interested members will come together to participate in a day of joint strategic planning.

New Name for the *Newsletter*. The Board selected a new name for the *Newsletter*. Watch for the next issue of the *Newsletter* that will unveil "TASH Connections" as the new name of our monthly magazine.

New Name for TASH: The Board unanimously agreed that TASH is in need of a new name. A plan of action was discussed to address the issue of a name change. A membership survey has been completed. The Board established a broad-based ad hoc committee that will be charged with reviewing the results of the membership survey and, based on this input, making a recommendation to the board regarding a new name.

Awards - Plan for the Future: The Board reviewed the current awards to assure that as a group they reflect TASH's priorities. It was agreed that we should combine the Positive Approaches Award and the Collaboration Award into one "Achievement in Advocacy Award." This could go to a parent, self-advocate, professional, or other advocate who had made significant achievements in furthering the mission of TASH for full inclusion/participation. A new award category was added: The Outstanding Chapter Award. We will continue to present the Media Award, the Alice Hayden Award, The Thomas Haring Award, and, as appropriate, the Lifetime Achievement Award. Not all of these awards will necessarily be presented each year. The Reviewer of the Year and the Emma Rose Scholarship will be continued as well. Recipients of these awards will be listed in the conference program-but will not be announced at the awards ceremony.

Newsletter Topics: Each year the Board discusses topics for the upcoming year's newsletters. The Board suggested the topics below for this year's newsletters. If you would like to be a contributor to any of these issues, or if you have suggestions of authors for us to contact on any of these topics please contact Priscilla Newton, the *Newsletter* Editor, at pnewton@tash.org or by phone at: 410-828-8274, ext. 102.

- Balancing choice, safety and risk; self-determination; consumer control; managed care, long-term services and supports;
- Providing progressive residential supports; housing; homeownership family issues;
- Leisure & recreation issues;
- Assistive technology;

Continued on page 4

From the Executive Director

Continued from page 3

◦ Sexuality, friendships, supporting relationships;

◦ "Where science, advocacy and values meet"

◦ Inclusive education - specific strategies for making it work for kids with more severe disabilities;

◦ Community organizing; how one person can make a difference; disability access to the election process; acting locally in response to new political realities; chapter/local leadership;

◦ Transitions across the lifespan; planning and supporting milestones throughout one's life.

Committee Reports: The following committees provided reports. Highlights are noted.

- **Alice Hayden Award Committee**: Goals include establishing a timeline for award related activities, providing information about who Alice Hayden was on the website, listing past recipients on the website, and providing criteria for the award on the website.

- **Communication Issues Committee**: This group held a roundtable at the conference. They have revised two TASH resolutions related to communication and are working on developing a communication clearinghouse website. They are interested in offering a conference strand next year and developing a support and information dissemination group for augmentative and alternative communication (AAC) users.

- **Community Living Committee**: Goals include increasing the size and uses of the community living list serve, focusing on economic equity, and working collaboratively with other organizations that deal with economic issues and poverty as well as other disability advocacy groups.

- **Education**: This year's accomplishments include publication of TASH's first conference Yearbook and promoting and sponsoring three strands at this year's conference. Goals include facilitating dialogue on standardized testing and accountability and publishing a book of JASH reading related to inclusion.

- **Employment and Transition Committee**: Goals include writing a response to the Ticket to Work regulations focused on ways to include persons with significant disabilities; helping membership understand the implications of the Ticket to Work regulations, possibly through the *Newsletter*; continuing to build the importance of employment issues, possibly through a keynote at next year's conference; building connections between employment-based choice and the broader self-determination movement; and organizing a strand at next year's conference.

- **Guardianship Alternatives Committee**: Goals include a *Newsletter* article by or about the family that presented at this year's conference plenary session; organizing a TASH Tech at next year's conference; developing a TASH resolution on guardianship alternatives; publicizing the alternatives to guardianship; supporting efforts of self-advocacy groups; and working with TASH chapters to sponsor regional workshops on alternatives to guardianship.

- **International Issues Committee**: Goals include a campaign to ensure that the U.S. signs the convention on the Rights of the Child by Sept. '01; TASH pursuing membership in Inclusion International; work on the special issue of JASH devoted to international issues; and exploring the development of an international chapter as well as linkages with the Canadian Association for Community Living.

- **Multicultural Committee**: Goals include compiling information/directory of materials that are available in different languages; assuring website links to bilingual, multicultural and refugee organizations; seeking presentations on research related to non-english speaking households of children with disabilities; and providing a clearinghouse for information listed by topic and language. This committee is planning a crackerbarrel on immigration issues for next year's conference.

- **Parent and Family Committee**: This committee held a crackerbarrel at the conference. Goals include publishing short information sheets that explain research findings in plain language; organizing more networking opportunities; and getting the word out about TASH and opportunities to present at the TASH conference to more family members.

- **Personnel Preparation Committee**: This committee was instrumental in the publication of a special JASH issue on teacher education this year. Goals include finalizing a resolution on teacher education; drafting a resolution on related services personnel development; organizing both a strand and TASH Tech for next year's conference; setting up chat room discussions; and developing relationships with other teacher education organizations.

- **Positive Behavior Supports**: Last year this committee developed a resource list with contacts in each state and most Canadian provinces who could assist in finding positive behavioral support services. This year's goals include broad distribution of the resource list; continued work toward involving international human rights organizations in the fight against the use of aversive procedures; and lobbying for Federal support to build the capacity of states to support individuals with severe behavior problems.

- **Publications Committee**: Goals for this committee this year include increasing the circulation of JASH; making a recommendation for the next editor of JASH; and formalizing a mentoring relationship between incoming and outgoing editors.

- **Related Services Committee**: This year this committee organized a TASH Tech and presented a strand. Goals for the coming year include linking a website on related services to the TASH website, developing a resolution on the preparation

Continued on page 24

Introducing TASH's New Director of Governmental Relations, Jamie Ruppmann

I begin my tenure as the Director of Governmental Relations for TASH with a great deal of enthusiasm and pleasure to be working for and with an organization that I have respected, admired and supported for many years.

These introductory essays are difficult to write. One always feel concerned about setting an "enough about me, what do YOU think of me?" tone that will come across as boasting. Yet, there is the need to tell some details about my professional and personal life so TASH members will have an idea of who I am and why I am here.

My husband, Heinz, and I have two adult sons, Daniel and Stefan. Daniel is married and lives in Pennsylvania just outside of Philadelphia. We have two granddaughters, Francesca and Rebekah, ages 4 years and 9 months. Our youngest son, Stefan, lives with us in Virginia and has been working for the past nine years for the federal government.

My sons were both diagnosed early in their lives. First Dan, with learning disabilities and a seizure disorder, and then Stefan, with autism. Like many families, we struggled through the early "pre P.L. 94-142" days with no early intervention and no special education. The struggles of those years forged us into strong advocates for our sons. We came to understand very well the need for -- and the limits of -- public policy and services. We formed alliances with other families. We fought to maintain our leadership as primary decision makers for our family and were one of a handful of parents at that time who were seeking inclusion for our children with disabilities.

My work as an advocate has ranged from organizing grassroots activities at the local and state level to coordinating federal and state funded projects in Early Intervention, Parent Education and Systems Change. I've held the meetings, written (and bulk-mailed!) the newsletters, driven the speakers, coordinated the conferences, made the public testimony, testified in the Due Processes proceedings, attended the workshops, been appointed to the work groups and task forces, written the legislation and "sat in" the Rotunda of the United States Congress. After four years of working independently as a consultant, I am happy to be working collaboratively in a membership organization. I'm looking forward to assisting TASH members in achieving the public policy goals that will move us closer to the day when all citizens will be supported in achieving their self-determined dreams and hopes.

With the guidance of the Governmental Affairs Committee, chaired by Mike Auberger, and TASH Board liaisons, Marcie Roth and Lu Zeph, we will be moving ahead in the priority areas of MiCASSA, employment, education and international children's issues. Please don't hesitate to contact me with questions or suggestions for updating our web pages and publications. Members can reach me at the TASH office at (410) 828-8274, ext. 104 or by e-mail at JRuppmann@tash.org

Update on the Legislation Passed by the 106th Congress

Despite the failure of the Congress to act on behalf of MiCassa (Medicaid Community Attendant Services Act), several bills were passed that are of continuing interest to TASH members.

- The Ticket-to-Work and Work Incentives Improvement Act (H.R 1180, P.L. 106-170) amends the Social Security Act to expand the availability of health care coverage to allow individuals with disabilities to have meaningful employment without losing their Medicare and Medicaid coverage.

Public hearings are scheduled before the Social Security Ticket to Work and Work Incentives Advisory Panel. The advisory panel of the Social Security Administration (SSA) is holding a series of public meetings to obtain public input across the country. The purpose of these meetings and teleconferences is to collect ideas and reactions from all interested parties on the proposed regulations the Social Security Administration issued on December 28, 2000. These regulations spell out the program rules and the SSA implementation plans for the new Ticket to Work and Work IncentiveImprovement Act programs.

The new "Ticket to Work and Self-Sufficiency Program" is authorized by the Ticket to Work and Work Incentives Improvement Act of 1999. The program will provide SSA beneficiaries with disabilities with more choice in employment services, vocational rehabilitation services, and other kinds of support services to help them return to work. The Ticket program will pay the new providers of those services after a SSA beneficiary achieves a certain level of work.

For electronic information on the Ticket to Work and Work Incentives Improvement Act see the <www.ssa.gov/work> web site. To obtain a copy of the Notice of Proposed Rule Making, look under the topic SSA at <www.access.gpo.goc/su-docs/fedreg/a001228c.html> Information on the dates and times of the scheduled public hearings may be obtained by calling Conwal, Inc. at (703) 448-2300, ext. 338 or send an e-mail to robint@conwal.com

Continued on page 6

Update on the Legislation Passed by the 106th Congress

Continued from page 5

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Clinton Administration Follows through on Promises Made to the Disability Community

Before the change in administration in Washington took place, the Department of Health and Human Services announced the release of $70 million in grants to states aimed at supporting the American with Disabilities Act (ADA). The grants include $50 million in "Real Choice Systems Change Grants" that are designed to help states improve their health and long-term service delivery systems by expanding supports and opportunities for people with disabilities of all ages to live in their own homes and communities.
Grant funding may be directed toward improvements in quality assurance mechanisms, long-term service system reform and in demonstration projects.

Up to $15 million in grants and Section 8 housing vouchers are also to be made available to states to assist in the transition of people with disabilities of all ages from institutional to community-integrated housing.

Finally, grants up to $8 million will be made available to support states in improving community-based personal assistance services (PASS) designed to ensure maximum control on the part of people with disabilities. States may use the grants in the development and implementation of the infrastructure necessary to support long-term services that offer maximum consumer control.

The grant awards will be made to states by the end of September 2001. More information on the grants can be found on the HCFA web site at <http://www.hcfa.gov>

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Additional legislation passed by the 106th Congress includes:

- **The Children's Health Act of 2000** (H.R. 4365, P.L. 106-310) creates a National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control to (1) collect, analyze, and make available data on birth defects; (2) operate centers for the conduct of applied epidemiological research on prevention of those defects; and (3) provide birth defect prevention information and education to the public. The bill increases federal research and funding in a number of areas including lead poisoning and conditions such as autism, traumatic brain injury, Tourette syndrome and neurofibromatosis.
- **The Developmental Disabilities Assistance and Bill of Rights Act of 2000** (S 1809, P.L. 106-4020 reauthorizes programs that support individuals with developmental disabilities including State Councils on Developmental Disabilities, Protection and Advocacy Systems, and University Centers for Excellence in Education, Research, and Service. The law also provides funding to help states improve services to families and to develop a training program for direct support workers who assist individuals with developmental disabilities and their families.

Because the definition of developmental disability (not to be confused with developmental delay) is generic based on degree of disability, some individuals with learning disabilities may be eligible for services. ....

TASH Yearbook Order Form

The yearbook is a compendium of selected articles describing many of the conference presentations.

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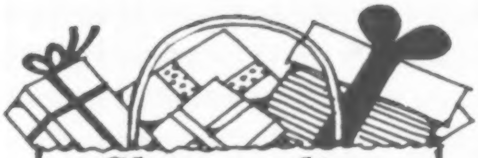

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Job Path seeks a Job Developer/ Marketing Representative

Job Path, a nationally recognized training and employment program for adults with developmental disabilities, places its participants in respected banks, law firms, department stores and other corporations. The program seeks a marketing representative (job developer) to develop job openings in the private sector.

RESPONSIBILITIES:

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- ✓ Participate in special projects

QUALIFICATIONS:

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STARTING DATE: Immediately

Send resume to:

Job Path
22 West 38 Street
New York, New York 10018
(212) 944 0564

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TASH 2000 Conference: "Moving the Edge"

TASH's 2000 Conference, "Moving the Edge," was held at the Miami Beach Fontainebleau Hilton and Towers from December 7-9th. The total attendance was around 1500. Although attendance was down from the previous year's conference in Chicago, the energy, enthusiasm, and excellent sessions that are associated with the TASH Conference were not! Many long time members were not at the conference this year ~ and we missed you! The conference is our time to renew commitments, energy, and action plans of the organization. We hope that each member will make plans to submit a proposal to present at the 2001 Conference!

Some of the highlights of the 2000 conference "Moving the Edge," were the opening address by our newly elected board President, Donna Gilles (see page 9), keynote addresses by Pat Mirenda and Oscar Arias (see page 13), a video tribute to Marsha Forest, and the presentation of the 2000 TASH Awards (see page 11.)

Highlights from Thursday's keynote address by Pat Mirenda will be featured in the next issue of the TASH Newsletter.

The tropical climate of Miami was a refreshing change and a source of enjoyment for participants. The price of a resort, however, was not! The overall consensus was that the property was too expensive — food was very costly and there were few viable options within walking distance. The majority of the evaluations reflected that attendees were satisfied with the organization of the workshops, conference program/book, and the overall quality of sessions. Many participants noticed the decrease in sessions and voiced their satisfaction with the "more manageable program." Some participants indicated that they were disappointed however, with the variety and balance of sessions; specifically, they felt that the conference had an over representation of education issues and too few sessions related to adults living in the community (employment, advocacy issues, for example). Please remember for this coming year -- **the content of the TASH Conference is built on proposals that are submitted**. If you want to see an increase in the number of topics in a certain area, encourage people who are doing progressive, cutting-edge work in that area to submit a proposal. Each single presentation is one of the threads that blends to make the fabric of the conference sturdy, vibrant, and rich. Make copies of the proposal form on pages 18-20 of this newsletter, and distribute it to folks who you see implementing the values of TASH everyday.

Participants were very pleased with the built-in lunch hour and requested the same format for both days of the conference. The roundtable luncheon was well received and there is support for having similar functions in the future. The Saturday morning poster sessions and breakfast was extremely successful. Over 75 posters were presented, and attendees, speakers and exhibitors were very pleased with the format, the complimentary breakfast and the on-site participation.

A variety of exciting poster sessions drew early morning attendees into the Exhibit Hall.

Future Conference Sites

We asked participants to rank their preferences for future conference locations in 2005 and 2006. The cities that drew the most votes were Anchorage, Seattle, and Edmonton or Montreal (Canada). The primary desire of conference attendees is that future locations be affordable for all participants. Specifically, attendees are requesting sites that offer more affordable hotel rates, airfare and meals.

We recognize that affordability is a major concern for most attendees, and we will continue to do everything within our power to meet the needs of conference participants.

Italy Seminar

Education in Italy: An Inclusive Approach

May 16-June 11, 2001
Syracuse University

Why study inclusive education in Italy? United Nations observers cite Italy's programs as the most inclusive in the world. There are site visits to schools in Rome, Florence, Bologna, Parma, and a rural village near Naples; guest lecturers from local, regional and national levels.

Time is planned for enriching cultural experiences involving the history, art, and architecture in Rome, Florence, Venice, Parma, Pompeii, and Orvieto.

Write or call Dr. Carol Berrigan, Seminar Director, of Syracuse University for more program information at: Center on Human Policy, Syracuse University, 805 S. Crouse Avenue, Syracuse, NY 13244-2280; Phone: (315) 443-3851; E-mail: crberrig@mailbox.syr.edu

Donna Gilles
TASH President, 2000-2003

The 2000 TASH Annual Conference was a celebration of the 25th anniversary of TASH and the 25th anniversary of the IDEA and its predecessors. It is no coincidence that TASH was formed at the same time as the passage of the law that made education of all children and young adults with disabilities a realty.

The founders of TASH are strong advocates of people who had traditionally been denied access to education, work, and community living. TASH has grown since then, in size, diversity, and in vision. At the beginning, TASH supported the right and the reality for children who have been labeled with significant disabilities to be taught in their home schools with the same teachers and classrooms as their peers without disabilities. Our earliest TASH members were instrumental in creating successful instructional technologies that helped people with significant disabilities learn critical skills, demonstrating that indeed it was not only appropriate, but essential to educate all students. For a long time, we stood alone in our support of people with disabilities being schooled in general education classrooms. TASH members were among the key developers of successful support strategies that today define inclusive education.

In becoming more responsive to the advocacy needs of our membership and as more people with disabilities become active members, TASH began to focus on issues that affect adults with disabilities. TASH members advocated for people with significant disabilities working in real jobs with real pay and, along with supporters from other organizations, were instrumental in making competitive and supported employment realities for many people with disabilities.

TASH currently is at the forefront of the struggle to ensure that people with disabilities have the supports that they both desire and require to live in their own homes. In our vision, nursing homes and institutions are not an option, and people with disabilities and their families should be in control of the funding and the choices that define their vision of community living.

While inclusive education and inclusive work are becoming more of a reality every day, people with disabilities continue to be forced to select congregate living arrangements because of the lack of vision, creativity, and desire on the part of those who fund living options for people with disabilities. The recent attacks on the ADA have been about this very issue of the rights of people with disabilities to live in the community instead of institutions. Once again, TASH members along with other advocacy organizations have worked hard to making living in one's own home a reality for many people with disabilities.

TASH has been described as the radical fringe; a group of people who do not know what we are talking about; an organization that is unrealistic. But look at where we have come in 25 years. **TASH members have created the vision and developed ways of making the vision a reality to the point that TASH doesn't stand alone on these issues anymore.** TASH has truly been ahead of its time every step of the way. Our values are reflected in our resolutions, many of which are bold statements on controversial issues, some of which are opposed even by some of our members. But we continue to "move the edge" and we wouldn't be TASH if we weren't challenging people to constantly think in different ways.

What's next? We have the vision, we know how to make it work, we know how to financially support people with disabilities becoming full participants in all aspects of their communities. In spite of our wealth of knowledge and talent, there are hundreds of thousands of people who are still segregated in educational, employment, and residential settings. There are too many people who are still isolated from the very people who could be their friends and their supports. It is time. **TASH's strength is in its membership and each of you is an agent of change.** If you are not a TASH member, consider joining. And whether you are a member or not, make the commitment to do one thing per day that will lead to the cessation of segregating people with disabilities, even if only to reflect on your own attitudes and biases that might create barriers to realizing the vision of the full inclusion of people with disabilities — every person, every day, every place.

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

2000 Conference HIGHLIGHTS

moving the edge

2000 TASH Conference

Miami Beach, Florida · December 6-9th

TASH's annual event is known for its array of riveting and informative workshops and discussion groups...

Recipients of the 2000 TASH Collaboration Award describe the Circle Way Project.

The Ft. Lauderdale Children's Theatre engaged attendees with a wonderful performance of a musical written by Jeff Moyer.

At the end of a long but productive day what could be better than cake -- especially one that marks TASH's Silver Anniversary!

...designed to educate, inspire and...sometimes make you laugh!

John Irvin's workshop on hilarity therapy was as entertaining as it was educational.

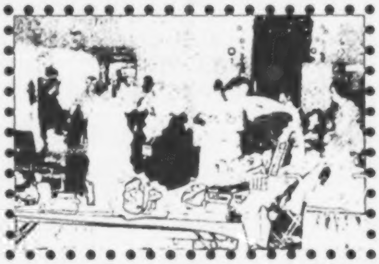
Jack Pearpoint (right) and Jan Nisbet shared a moving video tribute to Marsha Forest.

Wayne Sailor (left) presented a special Lifetime Achievement Award to Doug Guess.

The Collaborative Lesson Plan Book

Saturday morning's poster sessions and continental breakfast were big hits with presenters and attendees.

Of course, there was time for lots of special events, too!



Thanks to all who made donations and bid on items during TASH's first-ever Silent Auction! The event was a smashing success, raising almost $6,000 for the TASH Conference Scholarship Fund.

TASH's own Mary Bellone of the Central Office provided virtuoso entertainment at Friday's 25th Anniversary Reception.

2000 TASH AWARDS

2000 Thomas G. Haring Award for Research

Pamela J. Wolfberg, Craig Zercher, Joan Lieber, Karen Capell, Sonya Matias, Marci Hanson, Samuel L. Odom

This award is presented to the authors of a study of particular significance that was published in **JASH** within the two years prior to the annual conference. This years award goes to the authors of *"Can I Play With You?" Peer Culture in Inclusive Preschool Programs*, which appeared in **JASH** 199, Vol.24, No.2, 69-84. The article demonstrates scientific merit, and has made an important contribution to the disability field in terms of sociocultural influnces, implications for educational practice, and future directions for research.

2000 Collaboration Award

"Circle Way"

Center for Community Support (Mary Romer, Sally Sehmsdorf, and Leah Preston); Bridge Ministries (Mary Galvin, Bruce Knofel); Washington PAVE (Lindy O'Keeffe, Michelle Lehosky, and Chris Bily,); Parent to Parent (Robert Perretz-Rosales and Sarah Jolley)

The Circle Way ~ Statement of Intent

When I listen
A different reality becomes known to me,
When I reflect on what I hear
I am touched and changed
When I act on what I hear
We become a part of each other.

We who follow the circle way are committed
to honoring the harmony
that comes from a peaceful mind,
an open heart, a true tongue, a light
step, a forgiving nature, and a love of
justice.

Through this award, TASH recognizes a collaborative team of people whose work and accomplishments serve as an inspiration for other community efforts, and demonstrate creativity in supporting an individual or individuals to realize the goals of self-empowerment and full community inclusion. Circle Way is an exemplary project which has made a long-term commitment to the question of how to generate a local capacity to assist people with disabilities and their families, working from their hearts to engage the hearts of a growing network of people who are forging a collective, collaborative future.

2000 Alice H. Hayden Award

Meada Gwen Hall

TASH presents the Alice Hayden Award to a doctoral student who demonstrates potential for leadership in teaching, scholarship, and service on behalf of persons labeled with severe disabilities. Meada is a doctoral student in the Department of Special Education and Rehabilitation Counseling at the University of Kentucky. In addition to being a full-time student, she is director of a statewide project that uses distance learning technologies to prepare teachers of students labeled with moderate and severe disabilities in rural Kentucky. In additional to being a promising teacher educator and scholar, Meada's professors characterize her as an exemplary and innovative special education teacher, a strong advocate for students with disabilities and their families, and a force in the field of special education - whose drive is only likely to increase in the future.

2000 Positive Approaches Award

Robert Horner and George Sugai

This award is presented for contributions which have served to advance non-aversive intervention with persons who display challenging behaviors; have demonstrated outstanding efforts leading to the understanding of challenging behavior; and whose actions have advanced the use of non-aversive interventions and progress in the use of positive behavioral supports. Dr. Sugai's and Dr. Horner's research focuses on designing, validating, and implementing positive behavior supports, which has been successfully validated through data collection in various settings. Most notably, schools have recorded tremendous success through more positive student behaviors, improved student-teacher interactions, and higher academic performances.

2000 Emma Rose Scholarship

Billy and Jean Smith

Through the generosity of the Jacobs Family, TASH is able to award the Emma Rose Scholarship each year. The purpose of the scholarship fund is to foster the growth of parent advocacy and activism by honoring two parents each year who have made a difference in the lives of people with disabilities. This year the award is presented to the Smiths for advocating for their daughter, Carol and for championing the cause of equal opportunity for all.

Thank You!

to the following Official Sponsors for their support of the 2000 TASH Annual Conference!

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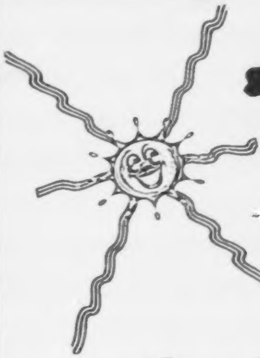

Thanks

to the 2000 TASH Annual Conference Volunteers!

We couldn't have done it without you!

To our Conference Exhibitors, your support is invaluable!

Many thanks to all of the Annual Conference exhibitors that supported TASH's 2000 meeting. We greatly appreciate the loyalty of those exhibitors that have been with us over the years, and hope that our newest exhibitors enjoyed the experience.

We look forward to having you be a part of the 2001 TASH annual event!

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Increase active participation
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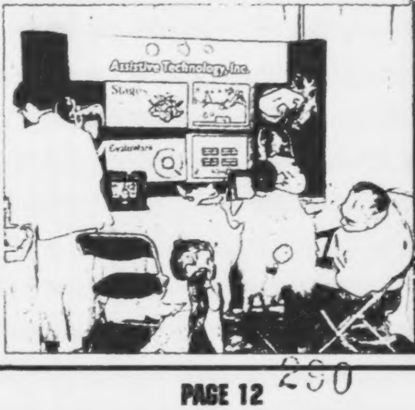
Assistive Technology, Inc.

KINETIC KIDS

EXCERPTS FROM 2000 KEYNOTE ADDRESS: DR. OSCAR ARIAS

"I applaud you for the sound principles and values on which your organization is based, and which are at the heart of your work: human dignity, social justice, peace, and compassion. I challenge you, then,as you go about the tasks of dialogue, teaching, and learning that have brought you to this conference, to hold these values ever before you. Turning values into action can present difficulties for all of us. But the difficulties will not be nearly as great as trying to grope our way in the dark, without the guiding lanterns that our values and principles provide."

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The Links between advocacy for persons with disabilities and working for peace

When I was invited to speak at this conference, I was told that there was a strong connection between my message of demilitarization and human security and the work of this distinguished organization. After reviewing TASH's Resolution on Peace and learning more about the organization, I have to say that I completely agree. There is a natural fit between working for an end to armed conflicts in the world and struggling for the rights of persons with disabilities.

A significant part of the affinity between my work and yours lies in the fact that war is the direct cause of millions of preventable and unnecessary disabilities. Land mines are a case in point, killing and maiming people both during and long after wars, as there is no timing device to signal to a land mine that a war is over. Fortunately, we now have a treaty in place, and clean-up efforts are being undertaken around the world that will go a long way towards ridding the globe of this particular menace. The success of the campaign to ban land mines was made possible by thousands of individuals and groups, like those gathered here, who value the dignity of human life over the mindless destruction caused by armed conflicts around the world.

Another thread that binds us together is our struggle for human rights. Many people, when they hear the phrase "human rights," think of such rights as the freedom from torture, and the freedom to express political views without fear of persecution. These, indeed, are among those rights listed in the United Nations Universal Declaration of Human Rights. They, and several others, pertain especially to individuals living in countries either at war or experiencing government repression or political instability. This is one class of human rights. Another class are those human rights which can go abused even in times of stable, democratic governance. These include, for example, the right to work, and the rights to food, clothing, housing, and medical care and necessary social services. While the former group of rights continue to be disregarded in situations of conflict around the world, the latter group are, amazingly, still not guaranteed in the world's most prosperous of democracies.

Let us first take a look at those human rights pertaining to war or political repression. As I mentioned earlier, and as can be read in the TASH resolution on peace, disregard for human rights in times of war results in innumerable preventable disabilities, both physical and mental. Political conflict is extremely complex, and consequently the battle to defend human rights in situations of conflict must consist of three major thrusts: one, to prevent these abuses from continuing to happen; two, to provide care and support for those who have fallen victim to the brutality of war; and three, to hold accountable those who perpetrate human rights abuses under the political cover of war.

I am aware that TASH, as an organization, has been particularly active on the second of these "battle fronts," that of supporting victims of armed conflicts and their families. As I am sure that you know more about this aspect of human rights work than I, I shall not dwell here, except to encourage you to keep up the good work. Instead, permit me to elaborate on two international efforts with which I am more directly linked, and which are fighting along lines one and three: preventing human rights abuses, and holding accountable those responsible for committing them.

In order to prevent human rights abuses, or any type of gross violence, at least two elements are necessary. I believe that we must attend to both the culture and mentality of violence that exists in the world, and to the continual production and spread of deadly weaponry. There has been much debate in recent years about whether people kill or weapons kill, but I tell you that this is a false dichotomy. Violent people with access to weapons is the deadly combination that the world, up to now, has not had the courage or vision to adequately address.

The most extreme consequences of weapons in the wrong hands can be seen in the numerous armed internal conflicts and episodes of "ethnic cleansing" and political repression that have happened, and continue to happen, throughout the world. Events in Rwanda, Kosovo, and East Timor, to name a few, provide us with awful examples. And what is perhaps the most troubling to those of us who live in what we consider to be civilized democracies, is that it is democratic governments that are making

Continued on page 14

2000 Conference Keynote Address: Dr. Oscar Arias

Continued from page 13

the weapons of destruction easily available to those carrying out such violence. Saddam Hussein sits atop a powerful arsenal that was supplied by Western governments when Iraq was thought to be the "safe bet" in its conflict with Iran. France provided much aid to the genocidal government of Rwanda. The military equipment used against pro-independence groups in East Timor had been previously supplied by Great Britain. And the list goes on.

While some human rights requirements do exist on international arms trade, they are generally of a voluntary nature, and easily overridden when a government perceives an economic or strategic reason to go ahead with a sale to a government or group with a poor human rights record. An example of this was President Clinton's approval of nearly one billion dollars in military aid to Colombia, a country which has been submerged in civil war for more than forty years. Although Colombia's military does not currently meet human rights requirements written into U.S. law, the president simply waived those requirements and went ahead with the aid.

It is clear that the interests that arms manufacturers and first-world governments pay heed to are not those of the individuals likely to be harmed or killed by the weapons they sell to undemocratic regimes. Instead, they act based upon their own financial interests, or short-term political alliances with groups considered to be "the lesser of two evils" — alliances which backfire as often as not. It is for this reason that I have been advocating, since 1997, an International Code of Conduct on Arms Transfers. As of today, eighteen other Nobel peace laureates have signed onto the Code, which calls for a ban on transfers of weapons or military technology to governments that violently repress fundamental democratic rights, are guilty of gross violations of human rights, or that commit acts of armed international aggression.

These measures seem so logical that it is difficult to conceive of the huge obstacles that stand in the way of their adoption by the world's leading democracies. Disgracefully, the biggest such impediment is the formidable economic and political clout wielded by the arms industry throughout the world. The situation is daunting, and yet we have hope because thousands of individuals, groups, and community leaders have expressed their faith in the Code as both morally sound and politically necessary. It is these people, and the force of their convictions, that turn possibility into progress, and turn impractical ideas into reality. Victor Hugo once said, "There is one thing stronger than all the armies in the world, and that is an idea whose time has come." I submit to you that it is time for a new ethic regarding weapons manufacture and sale, and that if governments and arms makers resist, in the end the people will convince them otherwise.

> *Let us be very clear about the distinction between national security and human security. National security was the old paradigm, the principle used to justify a hollow peace based on secure borders. Human security is the newer thinking, which recognizes that secure lives rather than secure borders produce real peace. Where national security demands management of conflicts, human security demands that we devote energy and resources to meeting the real needs of people rather than the imagined needs of the military establishment.*

Let us turn now to an important effort that is taking place internationally with regard to the third "battle front," if you will; that of holding abusers of human rights accountable for their crimes. For when we run up against the limits of prevention, and abuses do happen, impunity for the authors of such acts is the worst type of salt rubbed into the wounds of the victims and their families, and seriously hampers the healing process. The international community has recently taken steps in the right direction by establishing temporary tribunals to investigate and try war crimes in Rwanda and the Balkans. However, both their geographical specificity and the fact that their work has been purely retrospective limit the effectiveness of such tribunals in deterring human rights abuses. What is truly needed is an international and permanent body charged with the function of trying suspected war criminals and human rights abusers. Because of its permanent status, its existence alone would serve to deter would-be violators of human rights who might otherwise be able to act with impunity. Moreover, by ensuring that the perpetrators of heinous crimes are brought to justice quickly, an International Criminal Court would help conflict-torn nations on the road to reconciliation and recovery.

A movement to establish just such a body has been underway.for several years now. The Coalition for an International Criminal Court (ICC) scored a major victory in Rome in 1998, when an overwhelming majority of delegates at a diplomatic conference expressed their support for an ICC. Since then, 115 nations have signed the treaty and 22 have ratified it. Sixty ratifications will be necessary for the treaty to take effect, and it is clear that the most elusive will be that of the United States, a country which has time and again shown its resistance to submitting its citizens to the authority of international bodies. I tell you that unless the U.S. is willing to join the rest of the international community in condemning war crimes and crimes against humanity —including those committed by its own soldiers —it will be impeding progress toward a world where swift justice is available for those who fall victim to the brutal consequences of war. Most of you here are citizens of this great country, and I implore you to take whatever political actions are available to you to press your government to support the establishment of an International Criminal Court.

My friends, let us now turn to what I have termed the second type of human rights, those which rise to the forefront in times of peace: the right to employment and a decent standard of living, and the right to necessary health and social services. I have called these "the human rights of

Continued on page 15

2000 Conference Keynote Address: Dr. Oscar Arias

Continued from page 14

> *If we are honest with ourselves, and if we have the wisdom to take a long-term perspective, we will understand that there can be no peace without justice. For peace means more than the silence of guns. Peace is a process, a way of life, a way of solving problems and of resolving conflicts. It requires us to work and live together.*

peace time" in order to differentiate them from the human rights that are most often violated during wars. And yet, can we truly say that there is peace when such basic rights are denied?

If we are honest with ourselves, and if we have the wisdom to take a long-term perspective, we will understand that there can be no peace without justice. For peace means more than the silence of guns. Peace is a process, a way of life, a way of solving problems and of resolving conflicts. It requires us to work and live together. And, I promise you, where there is an absence of effort to achieve a true peace based on justice, the guns will not remain silent forever. The frustration of the marginalized people of the world regularly explodes into violence, reminding us that until justice is guaranteed for all individuals and groups, our world will not be able to enjoy the peace that we all long for.

In order to achieve a lasting peace with justice, and to guarantee this second group of human rights, what our world's governments and peoples will need is to undergo a shift of perspective. The change required is to move from the concept of "national security" to the concept of "human security," which puts individual human beings at the center of policy decisions. Again, this is something which seems logical and obvious — that policy is useless if it does not respond to the needs of real people — and yet so much of what passes for sound policy today does anything but take into account its effects on individuals.

Let us be very clear about the distinction between national security and human security. National security was the old paradigm, the principle used to justify a hollow peace based on secure borders. Human security is the newer thinking, which recognizes that secure lives rather than secure borders produce real peace. Where national security legitimizes the use of force for the protection of states' strategic interests, the idea of human security recognizes that poverty, hunger, and disease are forms of violence that have no justification. Where national security demands management of conflicts, human security forces us to think more holistically about the causes of conflict and instability. It demands that we devote energy and resources to meeting the real needs of people rather than the imagined needs of the military establishment. And it makes us pose hard questions to the policy-makers and arms merchants who insist upon creating an ever more dangerous and potentially explosive world, at the expense of creating real opportunities for the poor and marginalized to live lives of dignity. Human security goes far beyond a concern with weapons and fortifications - it is a concern with human life and well-being.

There is an urgent need for human security thinking to be adopted by today's world leaders. Nearly a billion people in the world are illiterate, and 1.3 billion live on an income of less than one dollar per day. More than a quarter of the people in the developing world have no access to safe water, and more than half have no access to sanitation. When we are faced with these truths, how can we continue to spend outrageous amounts of money on fighter planes and tanks, or even more nonsensical, on the continued development of nuclear missile systems?

And yet we do. In relatively well-off democracies as well as in many poor countries, military spending is out of proportion with spending on people's basic needs. This is the surest hallmark of a government that continues to cling to the national security model, while its people go hungry, suffer the humiliation of unemployment, and lack access to the most basic health and social services. The sad fact is that many countries spend more on their militaries than they do on health, and that countries such as Pakistan, Myanmar, Eritrea, and Burundi spend more on their militaries than they do on health and education combined. And what is military spending buying in these countries? Governments build up supplies of tanks and weapons to defend people who are dying in the streets and in overcrowded hospitals from hunger, malnutrition, and preventable diseases. Instead of going to school and paving a path to a brighter future, children learn how to throw stones and shoot rifles, and age-old conflicts are tragically perpetuated in the youngest generation.

It is my strong belief that military spending represents the single most significant perversion of worldwide priorities known today. To give a concrete example of this, let me make clear just how little of military spending would have to be diverted to reach universally desired human development goals. It is estimated that 780 billion dollars was spent on military technology and training worldwide in 1999[1]. According to the UN Human Development Program, just five percent of that amount would be sufficient to guarantee basic education, health care and nutrition, potable water, and sanitation to all of the world's people. And yet, instead of investing in the health and education of their people, poor countries continue to buy weapons, and rich countries continue to supply them, all in the name of "national security." Ask any child on the streets of India, Burundi, or Myanmar whether she would rather have bread to eat and a school to go to or a fighterjet to protect her, and you will have the obvious answer that national security means nothing in the absence of human security.

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[1] SIPRI Yearbook 2000: Armaments, Disarmament and International Security. Oxford UP: Oxford, 2000.

Continued on page 16

2000 Conference Keynote Address: Dr. Oscar Arias

Continued from page 15

To give an example of what is possible when human security takes priority over military spending, let me tell you about my country, Costa Rica. In Costa Rica there is no standing army. This provision was written into our constitution in 1949. During the half-century since then, Costa Rica has consistently been characterized as the most stable democracy in Latin America. With this sort of political calm, Costa Rica's leaders have been free to focus on the welfare of the country's people. As a result of having only minimal security spending in the form of funds for police, the Costa Rican government is able to dedicate almost a quarter of its national budget to education, and the adult literacy rate exceeds 95 percent. Moreover, the quality of health care in Costa Rica is very high, and Costa Rican life expectancies are comparable to those in the United States and Europe. It was the virtual elimination of military spending that made this progress possible. At the same time, we have found that not having an army has not, as some might fear, left us more susceptible to attack or encroaching violence from neighboring countries. By abolishing our armed forces, we gained a moral force which has become our best defense.

My friends, the initiatives which I have outlined here are just some of the possible ways to work for peace and justice in the world. There are so many different levels on which to have an impact in this struggle, from political action, to community participation, to simply being the best individuals we can be. As members of an organization that advocates for persons with disabilities, you understand the importance of collective action on behalf of those whose voice might otherwise go unheard. You also understand the capacity and responsibility of each individual to act. There is no question that individuals are capable of achievements that have a lasting impact on their surroundings, and even on their country or the world, and that this impact can be multiplied by grassroots organizations like this one, which are capable of shaking the foundations and waking up a society that has been sleeping. I commend you for your work in raising the visibility of both the accomplishments and the unique needs and rights of persons with disabilities, and for making a public call for the respect of the worth of each individual, regardless of race, creed, national origin, gender, sexual orientation, or disability. I also applaud you for the sound principles and values on which your organization is based, and which are at the heart of its work: human dignity, social justice, peace, and compassion. As you all well know, these values are not specific to the community of persons with disability. They are, rather, values which are universal to the human community, and which should underlie all of our efforts at building ever-better societies which are respectful of all aspects of the amazing diversity of humankind.

I challenge you, then, as you go about the tasks of dialogue, teaching, and learning that have brought you to this conference, to hold these values ever before you. Keep them in mind as you discuss education, family, and community. Mull them over during sessions on employment, health care, and discrimination. Any organizational theorist will tell you that an organization is most effective when it is responding directly to its mission and core values. And, more importantly, any spiritual leader will tell you that a person that has achieved inner peace is a person who has defined his or her values and is attempting to live by these on a daily basis. Turning values into action can present difficulties for all of us. But the difficulties will not be nearly as great as trying to grope our way in the dark, without the guiding lanterns that our values and principles provide.

And if your courage ever fails you, or if you fall victim to the belief that the actions of one person are insignificant, remember these words of Robert F. Kennedy:

"It is from the numberless diverse acts of courage and belief that human history is shaped. Each time a man stands up for an ideal, or acts to improve the lot of others, or strikes out against injustice, he sends a tiny ripple of hope, and crossing each other from a million centers of energy and daring, those ripples build a current which can sweep down the walls of oppression and injustice."

As you go about working to put the values of human dignity, social justice, peace and compassion into practice, and calling upon society to live up to these same ideals, I am confident that you will continue to make a world of difference in the lives of individuals and families around the globe. You, as an organization, have been doing so for twenty-five years. And I am convinced, my friends, on the dawn of a new century and new millennium, that the best is yet to come.

Kentucky TASH

is sponsoring a full-day conference

"Equal Justice for All"
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Sheperdsville, Kentucky

Highlights include a morning session with Bob Perske and afternoon breakout sessions.

For more information, please call 502-459-5292.

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Qualifications:

1. Qualify for Oregon Handicapped Learner License or a Severely Handicapped Learner's License

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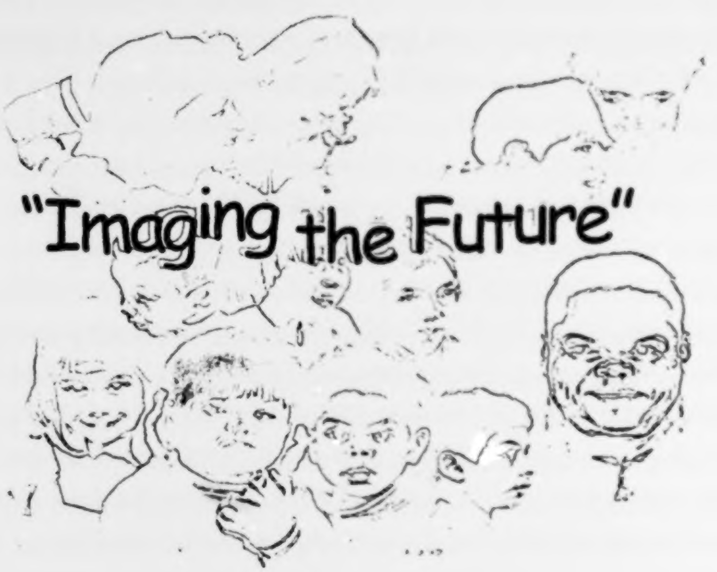
Lane ESD is located in Eugene, Oregon, a city of 125,000 situated at the southern end of the Willamette Valley about 100 miles south of Portland. Lane County's 4,500 square miles extends from the Pacific Coast to the Cascade Mountains. From Eugene, coastal beaches are one hour away to the west and snow skiing is one and one half hours to the east.

Eugene and its surroundings provide an ideal living environment, rated one of the best in the United States. Outdoor and cultural activities abound. Eugene is home to the University of Oregon and Lane Community College. Education is a high priority for the citizens of Lane County.

For more information or an application call Carol Knobbe at (541) 461-8264 or Brenda Jones at (541) 461-8202. A position posting is available at our web site www.lane.k12.or.us. An official Lane Education Service District application form must be submitted in order to be considered for this position.

TASH Announces a Change in Location for 2001 TASH Conference

The 2001 conference was scheduled to be at the Anaheim Hilton in California in early December. We will be moving the location and dates, however the exact location is not confirmed at this time. Every effort is being made to keep the conference in Southern California, or the West Coast, and to hold the conference in November or early December.



Artwork reprinted with permission from Martha Perske from Perske: Pencil Portraits 1971-1990 (Nashville: Abingdon Press, 1998)

We have held a contract with the Hilton Anaheim property for several years. At the time of contracting, and in the contract itself, the hotel states that they are in full compliance with the ADA. In August of 2000, TASH staff Denise Marshall made a site visit to the property and found that in fact the property, in our estimation, is not in compliance. The main issue of contention is the fact that the hotel does not have any roll-in showers. At that time, we stated to the hotel that per the ADA, 16 rooms with roll-in showers needed to be complete. We further told them that we wanted them in place before we held the TASH Conference. The hotel informed us that they were issued a court document which waived the requirement, as the hotel was built prior to the ADA and according to their engineer, the concrete slabs upon which the bathrooms are built are too thin to accommodate roll-in showers. This process also revealed that the original lawsuit, was brought against the hotel by a TASH member, and is currently under appeal.

In support of enforcing compliance with the ADA and of our member who filed the suit, the TASH Board and Conference Committee unanimously agreed that unless the hotel submitted a plan for installing the showers, TASH would not financially support this property and would move the conference to another location. The Anaheim Hilton and Hilton International have pledged to continue to investigate the issue in hopes that an acceptable solution will be found. In the meantime, they have agreed to release us from the contract without requesting adherence to the significant financial penalty for cancellation.

TASH has a long-standing relationship with Hilton International, and we appreciate the sensitivity and seriousness with which they dealt with this issue. If you have ever attended a TASH Conference, you know that we take over entire hotels, occupying over 800 rooms on peak attendance nights, utilizing general session rooms for 2400 people and over 26 breakouts at a time. The task of finding an alternate location with availability in this short of a time period is not a simple one. We are working feverishly, and expect an decision soon. Certainly the location will be established well before the March 31st deadline for submission.

All that notwithstanding, the call for presentations is out! The guidelines to submit an application to present follow on the next two pages.

The TASH 2001 Conference Committee has identified interest in presentations that address the theme "*Imaging the Future*." Proposals may be submitted on topics that demonstrate innovation, collaboration, energy and daring. Stories and strategies that have changed images, attitudes, systems, and empowered people to realize the full inclusion of people with disabilities are of particular interest.

We are looking for sessions that are presented by teams of folks (individuals with disabilities, family members, advocates, and professionals). We are hoping that sessions will be geared to everyone, and use techniques that engage the audience, either through discussion, activities, or other formats such as skits, singing, or drama. The conference committee is making a request this year for presentations that are delivered in Spanish.

Help ensure that the conference is filled with a rich variety of cutting-edge sessions by sharing copies of the call in this issue of the *Newsletter*, or call us at 410-828-8274, ext 109 to request an updated one.

Check the web at www.tash.org for updates on location and dates. You can also call Denise at 1-800-482-8274 (or 410-828-8274) extension 103, e-mail to dmarsh@tash.org; Kelly Nelson at extension 105 or e-mail to knelson@tash.org; or look for further updates in the February TASH *Newsletter*.

Guidelines for Submission

The TASH Conference has many events and sessions. Main features of the conference are the poster and breakout sessions. The poster session is a grand event! Over 100 posters are presented during breakfast with 2000 participants in attendance. In addition, there are over 350 cutting edge breakout sessions on a broad range of topics. All sessions are selected from proposals submitted to the Central Office of TASH. Proposals must be postmarked by March 31st. Each proposal is then sent to a review committee, whose members select the proposals that will be presented at this year's conference.

1) ***If accepted to present,*** **All presenters are required to pay conference registration fees.** TASH relies solely on membership and conference registration to be an effective organization. We strongly encourage presenters to be TASH members. International TASH members, self-advocates, parents, and family members are eligible to register at a reduced rate.

2) **TASH encourages presentations that are made through partnerships or that demonstrate collaboration.**

3) **Please complete all sections of the application. A description or abstract of the proposed session must be sent along with the completed application, postmarked by March 31, 2001.** Abstracts should (1) describe the topic or issue addressed, (2) provide an overview of the content, (3) describe the importance and contributions of the session, and (4) describe the session format - i.e. skill-building, program discussion, panel, etc.

4) **Proposal content must reflect the values and resolutions of TASH**. TASH is dedicated to disseminating information that reflects both the ideals and the pragmatic realities of pursuing the goals of equity, social justice, diversity, and full school, community, and work inclusion for people with disabilities. The proposal title, description, and all content of presentations must use "people first" language, and must relate to supports or issues that are inclusive and community-based. **Presenters need to ensure that materials for the session are accessible to a broad range of ability levels, and are made available in alternative format, such as computer text files or large print.**

5) **Please limit the abstract to 300-600 words (1 - 1 1/2 pages).** Do not send any other materials. You may submit the information on the application form or in alternate format, as long as all of the information requested is included. The form is available to download from TASH's web page: www.tash.org. You must, however, print and mail the form as per the guidelines. Please **DO NOT** email your proposal, as we cannot assure receipt or legibility of electronic transmissions.

6) In requesting the session format, please keep in mind that 1 hour and 2 1/4 hour presentation slots are limited. **Poster sessions are "exhibits" that allow personalized opportunity for discussion.** These sessions are highly interactive and valuable.

7) Once received, abstracts are forwarded to three reviewers for scoring. **Proposals are rated on the following criteria:** 1) relevance to TASH mission, 2) interest to TASH members, 3) extent to which information is state-of-the-art or cutting-edge, 4) the practicality of content, and 5) the clarity of the proposal. Scores are then tallied and ranked.

8) At times letters of acceptance get lost, or go to an incorrect address. **Letters indicating if proposals have been accepted are sent at the end of June.** Do not assume that your proposal has not been accepted if you do not receive a letter. Call the office to check on the status of your proposal. **Letters are sent to the coordinator to indicate if the session was accepted or not accepted. It is the responsibility of the session coordinator to notify co-presenters of acceptance.**

The 2001 TASH Call for Presentations is available in alternate format upon request.

2001 TASH Conference Presentation Application

Please complete all sections of this form. Submit 3 copies of the form and 3 copies of the required attachments listed below. ***Mail by March 31, 2001 to:***

Kelly Nelson, TASH, 29 West Susquehanna Avenue, Suite 210, Baltimore, MD 21204
Questions? Phone: 1-800-482-8274 x105 or 410-828-8274 x 105
Sorry, faxed or e-mailed copies cannot be accepted.

Date Received: ____________
Session Code: ____________

COORDINATOR (You may only submit as a session coordinator on **one** proposal) :

____

ORGANIZATION : ____

ADDRESS: ______________________________________ CITY: ____________________

STATE/PROVINCE: ____________________ COUNTRY: ____________________ ZIP/POSTAL CODE: ____________

DAYTIME PHONE: ______________________________ HOME PHONE: ____________________

FAX: ______________________________ E-MAIL: ______________________________

The above address is: ☐ HOME ☐ WORK ☐ OTHER ______________________________

Session Information *Please attach the following information:*

- Session Title
- A short (40 word) description of your session that will be used in the conference program. Participants will select which session to attend based on this description, so write it with care!
- A one page abstract that describes the session.
- A list of all co-presenters, including name, address, phone, fax, and e-mail for each person.

Requested Session Type:

(Please check only one)

☐ **Breakout Session**
☐ **Debate**
☐ **Performance**
☐ **Crackerbarrel or Discussion**
☐ **Strategic Gathering or Planning Session**
☐ **Art Display**
☐ **Poster Session**

☐ I understand that it is my responsibility to contact co-presenters regarding their participation in this session and to inform them of the requirements listed on the guidelines for submission (including payment of conference registration fees) if accepted.

Signature *(required)*: ______________________________

Session Length (not applicable for posters or art displays):

☐ **1 HOUR SESSION**
☐ **2 HOUR & 15 MINUTE SESSION**
☐ **TASH TECH Workshop (will be held from 1:00 - 6:00 PM)**

Applicable Interest Area *(This category determines which committee reviews your proposal. Please pick only one)*

☐ ADVOCACY
☐ AGING
☐ ASSISTIVE TECHNOLOGY
☐ CREATIVE/PERFORMING ARTS
☐ COMMUNICATION
☐ COMMUNITY LIVING/HOUSING
☐ CRIMINAL JUSTICE
☐ INCLUSIVE EDUCATION
☐ URBAN EDUCATION
☐ HIGH SCHOOL INCLUSION
☐ INTERNATIONAL INCLUSION
☐ STATEWIDE ALTERNATE ASSESSMENT
☐ EARLY CHILDHOOD
☐ EMPLOYMENT
☐ ETHICS/RIGHTS
☐ FAMILY
☐ GUARDIANSHIP ALTERNATIVES
☐ GOVERNMENTAL AFFAIRS
☐ LEISURE AND RECREATION
☐ MANAGEMENT ISSUES
☐ MULTICULTURAL
☐ PARAPROFESSIONAL
☐ PERSONNEL PREPARATION
☐ POSITIVE APPROACHES
☐ RELATED SERVICES
☐ RESEARCH
☐ SELF-DETERMINATION
☐ SPECIAL HEALTH CARE NEEDS
☐ SPIRITUALITY
☐ SEXUALITY/ SEXUAL EXPRESSION
☐ STUDENTS WHO CHALLENGE SCHOOLS BUT WHO DO NOT HAVE "SEVERE" DISABILITIES
☐ TRANSITION

Other related interest areas to which this session would apply:

____

____

TASH wishes to acknowledge the generous support of our newest lifetime members

Jacqueline Farmer Kearns ~ Nicholasville, Kentucky
Victoria McMullen ~ University City, Missouri
Lisa O'Brien - Huntington Beach, California
Kathy O'Connell ~ Syracuse, New York
Kathryn D. Peckham-Hardin ~ Camarillo, California
Dr. Cathy L. Pratt ~ Bloomington, Indiana
Patti Scott ~ Franklin Park, New Jersey
Philip R. Smith ~ Montpelier, Vermont
Mark Wurzbacher ~ Takoma Park, Maryland

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.

Expanding Horizons:

Partnerships for Quality Outcomes

Training Conference

MARCH 8-9, 2001
DOUBLETREE HOTEL, PENTAGON CITY
ARLINGTON, VIRGINIA

- *Self-determination*
- *Individual Outcomes*
- *"Ticket to Work"*
- *Workforce Investment Act*

Registration info:
(202) 274-3416
dclark@sjcs.org

Keynote Speaker:
Mr. Robert Gettings,
Executive Director of the National Association of State Directors of Developmental Disabilities Services

Sponsored by:
St. John's Community Services & University of Maryland CRP/RRCEP

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VANDERBILT UNIVERSITY-PEABODY COLLEGE

This department is nationally ranked as one of the leading programs in special education. The faculty are engaged in innovative research and development projects and support a rigorous, research oriented doctoral program. Master's degree programs include: Early Childhood Special Education, Behavior Disorders, Learning Disabilities, Severe Disabilities, Secondary Transition, and Visual Disabilities. Doctoral program emphases include Behavioral Disorders and Transition, Learning Disabilities, Early Childhood Special Education, Visual Disabilities, and Severe Disabilities. Generous financial support packages are available.

Applications are accepted on a continuous basis. For more information, visit the Web site at **wwwpeabodyvanderbilt.edu** or contact Lynda Wyatt, (lynda.wyatt@vanderbilt.edu), Department of Special Education, Box 328, Peabody College of Vanderbilt University, Nashville, TN 37203; (615) 322-8195.

Vanderbilt University has a strong commitment to diversity and actively seeks applications from minorities and individuals with disabilities.

Children and Adults with Autism Could be at Risk from Medication

An alert was issued recently calling attention to the fact that thousands of people with autism were treated with fenfluramine, a drug now suspected of causing serious heart problems. The drug has not been used frequently for autism since the 1990s, and many people with autism who took this drug, their families, and their current health care providers, remain unaware that they should consult their physicians about possible risks.

Fenfluramine and dexfenfluramine were also marketed as weight reduction drugs until they were withdrawn from the market in 1997 in the face of mounting evidence that they could cause serious, potentially fatal heart problems. Since that time, a class action suit in the United States was settled for $3.75 billion and individual court awards to former users of these drugs have also been awarded millions of dollars. A similar class action suit appears to be close to settlement in Canada.

In September 1997, Health Canada and the U.S. Federal Drug Administration (FDA) announced that fenfluramine and dexfenfluramine (a particular form of fenfluramine) were being withdrawn from the market. The manufacturer withdrew the drugs voluntarily at the request of the FDA. At the time of the withdrawal of the drugs, Health Canada and the FDA urged the public to stop taking the drug and recommended that anyone exposed to the drug consult a physician about possible damage to their heart.

While attention has been given to the weight loss effects of fenfluramine, little attention has been given to thousands of children with autism and other developmental disabilities who were given the same drugs. Many of these individuals and their caregivers remain unaware that they, too, are at risk for damage to their hearts. While the problems associated with fenfluramine often remain undetected, detecting them before acute problems occur can reduce risks and improve outcomes. These problems may be even harder to detect in people with autism and developmental disabilities who often have limited communication. According to Raffath Sayeed, a physician in private practice with a particular interest in the care of patients with developmental disabilities, it is important that all individuals who took fenfluramine consult their health care providers.

In 1982, the New England Journal of Medicine printed case reports suggesting fenfluramine might be a powerful tool in treating autism. Some reports suggested that it doubled the IQ of children with autism, improved their ability to focus, and eliminated disruptive behavior. By the late 1980s, controlled studies showed that the benefits, if any, were much more modest and limited to a few individuals. In addition, more unpleasant side effects had been noted. Some physicians continued to prescribe fenfluramine to children and adults with autism well into the 1990s.

People with autism or a history of childhood autism, their families, and health care providers should work together to determine if they were treated with fenfluramine. People who were treated with this drug should consult their current health care providers to determine whether they should have tests of the heart valve function. This may involve an echocardiagram, a noninvasive test, similar to an ultrasound.

For more information please contact Dick Sobsey, Director, JP Das Developmental Disabilities Centre, at 780-492-3755; or Raffath Sayeed, MD, Family Medical Clinic, Lloydminister, Alberta, Canada at 306- 825- 8877.

Waddie Welcome and his Circle of Friends were the recipients of the 1998 TASH Collaboration Award. It is with deep sadness that we report Mr. Welcome's passing on January 15, 2001. The following article is reprinted from the *Savannah Morning News**.*

Waddie Welcome got his wish to live where he could "smell food on a stove and could hear children playing."

Waddie Welcome didn't like nursing homes. Cold, sterile conditions, strangers as caretakers and distance from friends and family seemed to harm the Savannah man more than the cerebral palsy he had since birth. After all, Welcome had spent his first 70 years or so supported by his parents, Henry and Carrie, then his brother, Willie. No day-care programs. No respite care. No institutions.

Just family, residents in and near his Cuyler-Brownsville neighborhood and members of his church, Connor's Temple Baptist, pitching in to help a man whose limbs and mouth didn't work like most.

But parents die and siblings sometimes can't provide living conditions approved by well-intentioned neighbors. Officials were notified and placed Welcome in the first of series of health care facilities, where he spent the next 10 years. But Welcome longed to live in a home. His wish motivated a group of community members. Thanks to their work over the years, government assistance that once funded Welcome's nursing home stay was used to pay for him to live in regular homes with regular folks.

"What he wanted was to live with a family where he could smell food on a stove and could hear children playing," said Tom Kohler, coordinator of Chatham-Savannah Citizen Advocacy, Inc. and a Welcome supporter. Although unable to talk well, Welcome made his point to nursing home visitors that he didn't like it there.

Waddie Welcome
1914-2001

"We learned to pick up certain gestures," said Savannah attorney Lester Johnson. "It was always, 'I want to get out.'" "When we finally did it, it was a great feeling because he was so happy." Welcome got himself back home, with various families, close to his favorite fried chicken and sweets of his longtime friend, Addie Reeves, 99.

"I took care of him as my child," Reeves said. "He came to church every Sunday. He came in smiling." With institutional life behind him, Welcome thrived in the four or five Savannah homes he lived in for the past decade or so. He became perhaps the oldest person nationwide with cerebral palsy until he died earlier this month of liver cancer. Welcome was 86 and still at home.

A lover of women and socializing, Welcome used a wheelchair to attend celebrations around town, including the 1997 premiere of an award-winning documentary, "Waddie Welcome: A Man Who Could Not Be Denied." The "sensual, gritty optimist" knew how to motivate people of diverse colors and classes, Kohler said.

"The thing that people are surprised at is the depth and breadth of the people who care about him," Kohler said. What people find more shocking it that a charismatic senior citizen with disabilities opened the door for others to live in families, not institutions.

"Anyone in a nursing home who prefers to live with a family can now do that because of him," Johnson said.

Welcome found a way to live a real life. He found a way home. Welcome, a native of Sylvania, lived much of his life in the Cuyler-Brownsville neighborhood in Savannah. One of five boys, Welcome was never able to attend school because of his disabilities.

Welcome was named one of Chatham County's 10 most influential people of the decade in December 1999. He was a founding a member of the St. James Storytellers Group and a member of the Circle of Friends. He spent roughly the last 15 years influencing public policy to be more personal and less institutional.

Welcome and his supporters were the subject of a documentary film, "Waddie Welcome: A Man Who Can Not Be Denied," produced by the University of Georgia. The film has won top honors at three video and film festivals nationwide. TASH honored Welcome and several friends with its 1998 Collaboration Award in Seattle.

How does the latest rulemaking and legislation coming out of Capitol Hill affect you and your family? How can you join with others to make a difference and ensure that your voice is heard?

Join the TASH Governmental Affairs ListServe Today!

To sign up, go to TASH's site at http://www.egroups.com/subscribe/TASHGovAffairs

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From the Executive Director

Continued from page 4

of related services personnel, and exploring a special issue of JASH.

●***Special Health Care Needs Committee***: Goals include coordinating a strand for next year's conference, and disseminating information of different program models, different sources of support and funding, and various decision making models for determining support needs.

Plan for new resolutions: Several new resolutions had been proposed and are being worked on by committees. A small group of TASH members will be sought to review/revise a resolution that was sent to us on Electro Convulsive Therapy (ECT) and make a recommendation to the Board on this resolution. A number of other topics have been suggested on which to develop resolutions. The Board will review this list over the next few months and select those they view as priorities to work on over this year.

Are you interested in participating in any of this work? Do you have ideas, suggestions or concerns? We and the committees welcome your involvement. Please contact me by phone at 410-828-8274, ext. 101 or e-mail: nweiss@tash.org to discuss your suggestions or to contact the chairs of any of these committees.

University of
Maryland
College of Education
Department of Special
Education

The Department of Special Education at the University of Maryland, College Park, is currently recruiting students in need of certification and those who would like to pursue a masters degree in special education with an emphasis in severe disabilities. We are offering full tuition remission as well as book reimbursement to all full and part-time students.

In addition, we are also seeking qualified applicants in search of part-time assistantships; living stipends and benefits are available on a competitive basis.

Members of underrepresented groups are encouraged to apply.

Please contact Dr. Frances Kohl, Project Director, Low Incidence Personnel Preparation Grant at (301) 405-6490 or via e-mail at fk4@umail.umd.edu

The Herb Lovett Memorial Fund, Inc.

Third Annual Taking the Leap

Saturday March 24- Sunday March 25, 2001

American Visionary Art Museum
800 Key Highway - Baltimore, Maryland 21230
Phone 410-244-1900

"I have generally been interested in writing about what I am learning, and inviting others to comment and help along the way, rather than articulate some truth as if I had discovered it."

Herb Lovett, from edited PDD book outline

Please join us as we use Herb's outline to facilitate a conversation on our experiences around the issues of developmental differences.

Speakers:

- Anne Donnellan
- Brett Leimkuhler
- Judith Snow
- Doug Biklen
- Roger Banks
- Rob Cutler

Agenda:

Saturday

12:00 noon Registration
1:00 p.m. Tour of Museum
2:00 P.M. Keynote
3:00-6:00 P.M. Panel Discussion
6:00-8:00 P.M. Reception with Rabbit Award

Sunday

10:00 a.m. -12 noon Concurrent Sessions
12:00 noon Lunch
1:00 p.m. - 3:00 p.m. Concurrent Sessions

If you live with...	**you learn to...**
hostility	fight
criticism	condemn
ridicule	be shy
shame	be guilty
tolerance	be patient
encouragement	be confident
praise	appreciate
fairness	be just
security	trust
approval	like yourself

"Vision is the art of seeing things invisible."
Jonathan Swift

"Art is at its best when it forgets its very name."
Dubuffet

"I hope that we have come to a point in our history where we have started to recognize that: the end point of pure thought is probably death; that we are not going to think our way out of these problems; and that we require a new respect for the irrational, the intuitive and the felt. We are discovering that we need people who step out of the mold of what we created... to remind us who we are and who we need to be for one another."
Herb Lovett

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CALL FOR NOMINATIONS:
Editor of JASH

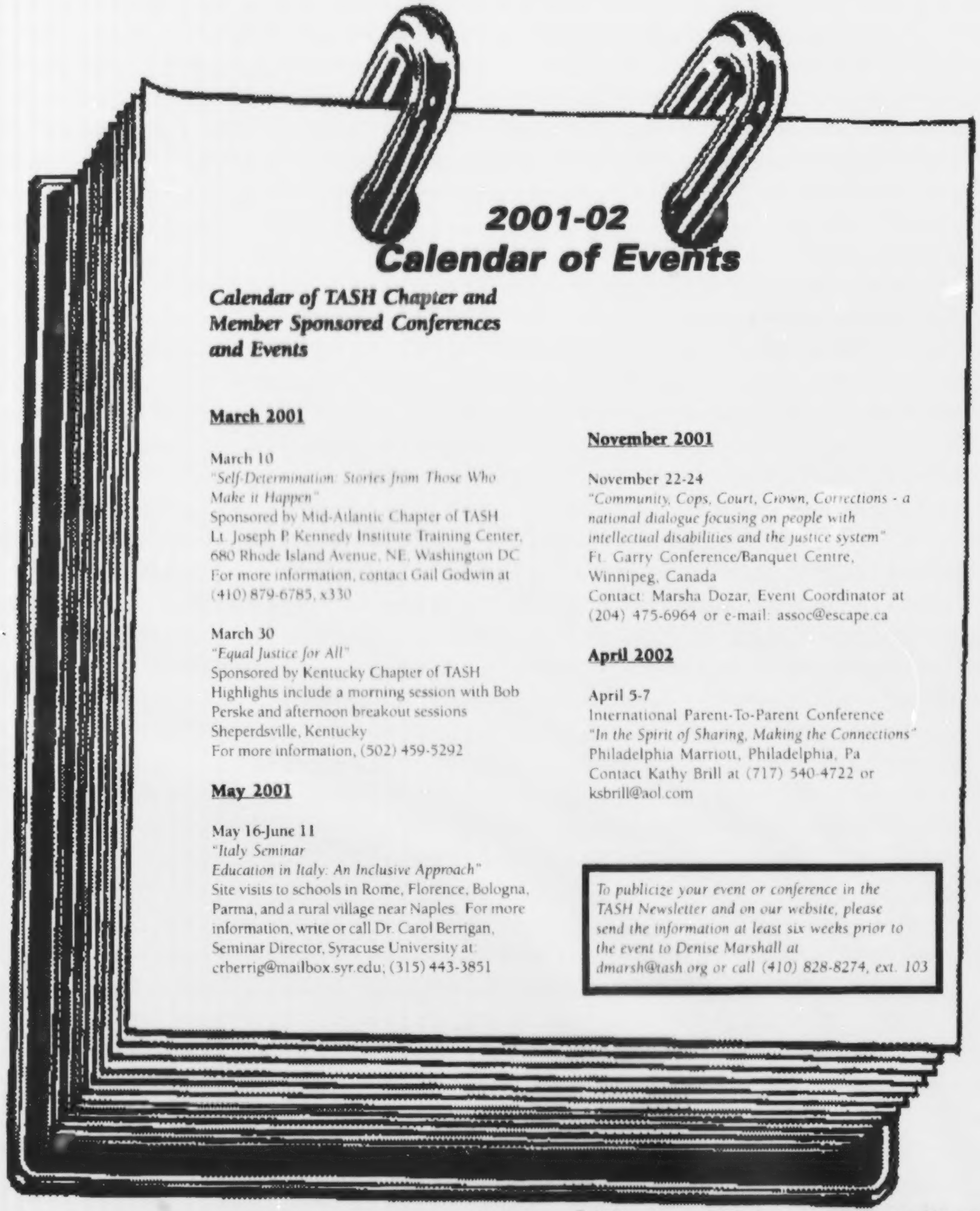
The TASH Executive Board and Publications Committee are beginning the search for the new Editor of JASH. The Editor serves a three-year term that will begin officially in October, 2001.

Nominations or direct applications are invited from TASH members with the experience and expertise described below. Applications from traditionally under-represented groups including people with disabilities, women, and people representing racial or ethnic minority groups are particularly encouraged. The following criteria will be used in making the selection decision:

1) Previous editorial experience as an Editor or Associate Editor of a scholarly journal in the field.
2) Previous authorship experience: publication in JASH within the past two years and /or substantial publication record in JASH and other journals.
3) Commitment to TASH resolutions and ideals.
4) Record of leadership in the area of severe disability, both within and outside of TASH.
5) Openness: willingness to consider new directions and innovative practices in the context of maintaining the Journal's commitment to excellence and scholarship.
6) Research skills: expertise in one or more research method commonly used in the area of severe disability, for example: within-subject designs, qualitative methods, and/or large-N descriptive, experimental methods.
7) General organizational skills: evidence of ability to meet important deadlines and organize major tasks.

If you are interested in being considered for this position or to make a nomination, please send a brief letter of nomination/application **by April 1st, 2001**, to Nancy Weiss, Executive Director, TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21212. You may also e-mail your nomination or notice of your interest to: nweiss@tash.org. Further application materials will be requested from finalists.

To receive a description of the process used in making the selection decision, please contact Nancy Weiss, nweiss@tash.org or by phone at 410-828-8274, ext. 101.



2001-02 Calendar of Events

Calendar of TASH Chapter and Member Sponsored Conferences and Events

March 2001

March 10
"Self-Determination: Stories from Those Who Make it Happen"
Sponsored by Mid-Atlantic Chapter of TASH
Lt. Joseph P. Kennedy Institute Training Center,
680 Rhode Island Avenue, NE, Washington DC
For more information, contact Gail Godwin at
(410) 879-6785, x330

March 30
"Equal Justice for All"
Sponsored by Kentucky Chapter of TASH
Highlights include a morning session with Bob Perske and afternoon breakout sessions
Sheperdsville, Kentucky
For more information, (502) 459-5292

May 2001

May 16-June 11
"Italy Seminar
Education in Italy: An Inclusive Approach"
Site visits to schools in Rome, Florence, Bologna, Parma, and a rural village near Naples. For more information, write or call Dr. Carol Berrigan, Seminar Director, Syracuse University at: crberrig@mailbox.syr.edu; (315) 443-3851

November 2001

November 22-24
"Community, Cops, Court, Crown, Corrections - a national dialogue focusing on people with intellectual disabilities and the justice system"
Ft. Garry Conference/Banquet Centre,
Winnipeg, Canada
Contact: Marsha Dozar, Event Coordinator at
(204) 475-6964 or e-mail: assoc@escape.ca

April 2002

April 5-7
International Parent-To-Parent Conference
"In the Spirit of Sharing, Making the Connections"
Philadelphia Marriott, Philadelphia, Pa
Contact Kathy Brill at (717) 540-4722 or
ksbrill@aol.com

To publicize your event or conference in the TASH Newsletter and on our website, please send the information at least six weeks prior to the event to Denise Marshall at dmarsh@tash.org or call (410) 828-8274, ext. 103

Diary of a Dad Up Against the Four 'D's

BY THOMAS BRADLEY

At first the teachers tried to tell us he was retarded. Then they tried to tell us there was nothing wrong with him.

Our son, David, was diagnosed with autism in 1987 when he was five years old. He has attended school here in Williford, Arkansas since the first grade. We have tried for many years to get the services guaranteed to our son by the Individuals with Disabilities Education Act (IDEA). The school district gave us no assistance in obtaining for David what, by law, is his right.

When he entered seventh grade, he went from having one teacher all day to having five. Right away it became an everyday battle to try to get him to school. We tried to find out what the problem was. He could not tell us; the teachers would not. The saga of our family's ordeal with our local school district and the lack of enforcement of IDEA on any level has been lengthy and painful.

September 1994. Meeting with school staff. Told them our problems, asked for help. The special ed teacher said David was "just having problems making the change from elementary to junior high school." After the first nine weeks, "everyone would have had time to adjust." We were to wait it out.

October 1994. Meeting with school staff. Told them our problems again, asked for help again. David's health teacher told us, "You're wasting my time trying to teach him." She suggested we get him some pottery lessons so he could learn to make a living someday.

We insisted that his teachers try to teach. We asked that staff be trained about autism.

The following week I got a call from the school. They told me to come get my son, that he had made an "unprovoked attack" on another student. I found that my son had pushed a boy who was threatening to blow him up with a bomb. The superintendent said that David "should have known better than to believe that."

A few days later, another "unprovoked attack." This time an older girl had been pestering David as he tried to eat breakfast. He moved to a different table to get away. She persisted until he tried to push her away. She hit him and choked him. The principal, at a disciplinary conference, suggested we take David to a different school. He was now "a disciplinary problem." I suggested that they were trying to make my son a problem when he was only defending himself. I again suggested staff training in autism.

We attempted to get assistance from Advocacy Services [Protection and Advocacy (P&A), a state and federally-funded legal assistance agency], but they told us they did not have the staff to handle all the problems in the state.

November 1994. We called a consultant to come observe our son at school and at home and make some recommendations for the school. The district told us they didn't need help. We filed for our first due process hearing. Opting for a pre-hearing conference, we heard the school district agree to consult with a university-affiliated program and try to learn how to teach our son.

Denying services.
Delaying due process.
Deceiving parents and children.

Those are the three Ds of special education.

In rural Williford, Arkansas,
there's a fourth D:
Death threats.

December 1994. We attended an IEP (Individual Education Plan) meeting with two behavior specialists who presented recommendations. There were also evaluations from autism specialists and Easter Seals. The superintendent of schools rejected all recommendations. He felt, he said, that David had "reached his intellectual peak" and probably would not succeed in high school.

For the next several months we continued to try to get the school to work with our son. But by this time things had gotten so unpleasant at school that the only way our son would stay there was if his mother, Diane, or I stayed at school with him. We took him out of the resource room after we learned that his teacher only gave him a workbook page and sent him to a corner while she worked with the other students.

At mid-term, we put our son into a beginning algebra class. During the first week of class he kept his coat pulled over his head, never once looking at the blackboard. At the end of the week, when tested, his grade was 100 percent.

Again we tried to get Advocacy Services to help us get an appropriate IEP (as called for by IDEA) and extended year services (summer education). Nell Bradley of their office was assigned to help us. We had several telephone conferences, but she never came to the school. We learned she was meeting with the superintendent and had agreed to put off any meetings until after school was out when it would be too late to get extended year services.

We were forced to hire a private attorney. Advocacy Services then said it would not be able to help us because we had a private attorney.

May 1995. We filed a second request for due process. On the hearing day in June, the district wanted to negotiate a settle-

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DIARY OF A DAD UP AGAINST THE FOUR 'D'S

Continued from page 28

ment. With the assistance of the hearing officer, we worked out what we thought was a pretty good IEP. The district agreed to hire an aide to take my place by my son's side, agreed to provide access to computers and software, agreed to provide training for staff, and agreed to classroom and curriculum modifications as recommended by experts. The hearing officer ordered the IEP implemented immediately.

August 1995. School started and the school district was already in violation of the IEP. I met with the superintendent who told me he had no intention of doing what he had agreed to do. After two hearings, the school board decided to remove the superintendent from any responsibility for implementing the IEP, putting a teacher in charge instead.

That helpful hearing officer, when we contacted her, said she had no responsibility once the hearing was over and the decision made. We had to start all over again. We again contacted Advocacy Services and were told they could not help us because we had hired a private attorney.

The 1995-96 school year was a disaster. The IEP was never implemented. We filed a state complaint. State investigators came in, discounted our evidence, told us the school was making a "good faith effort," that we were "expecting too much."

Soon several school staffers began a campaign to turn other parents against us. Teachers told parents and students they could not do anything for their children since they were having to do so much for David. In one open meeting, a teacher referred to him as "like some kind of mad scientist."

A parent contacted the Governor's office asking to have our son removed from the school. The Governor's office referred her to the State Department of Education. A department employee discussed David's IEP and his diagnosis with that parent, then followed the phone conversation with a letter containing further confidential information about him.

> *"Members of Congress, it is time to get real. Stop saying that IDEA requires schools to educate children with disabilities. It is untrue in Arkansas. According to the NCD report, it's not true in any state in the U.S. Don't give us hope with one hand and slap us down with the other."*

Advocacy Services declined to help us to fight these invasions of privacy, saying that while the Department of Education and the school district shouldn't be doing these things, Advocacy didn't want "to make a fuss that would just cause more trouble."

We found a new private attorney once the earlier one told us she could not afford to antagonize the hearing officer by making any complaints about him.

April, 1996. At our annual review conference, the school district proposed to throw out everything they had agreed to the previous year. The teachers felt they "didn't need the IEP," preferring to do "what we think best." We requested an independent evaluation. The district refused.

Spring and Summer 1996. We filed for due process again. The hearing officer denied us a hearing on half of the issues we raised, a violation of IDEA. Nor did we receive a hearing decision in 45 days, another IDEA violation.

We filed a complaint with the U.S. Department of Education's Office of Civil Rights (OCR). OCR declined to investigate. We notified OSEP (the Office for Special Education Programs), asking for a legal opinion about the state's actions. Thomas Hehir of OSEP notified the Arkansas Department of Education of the state's violations of Part B of IDEA, giving the state 30 days to correct the violations.

Four months later, Arkansas sent OSEP a letter saying, basically, that all state hearing officers had been advised to abide by the 45-day rule. End of intervention by OSEP.

August 1996. The hearing officer would not tell our attorney what the hearing rules would be. "I have a wide latitude," she said. "I pretty much make them up as I go along. Don't worry. I'll tell you when you break the rules." This same hearing officer, who had helped negotiate the settlement in 1995, found in favor of the district in 1996 and threw out everything she had helped us to negotiate. We appealed the decision to federal court.

In a lot of rural areas, the school district is the biggest employer. We have had death threat phone calls, break-ins, people stopping on the road and yelling at our house. When we got the phone calls traced, the prosecutor refused to prosecute. Once, when we got one of the death threat phone calls to court, and the people who made the call admitted to doing it, the judge found them not guilty anyway. Then he lectured them for about twenty minutes about why they shouldn't do it again.

When we have asked people to assist us by testifying in court about what our son needs, or about autism, or inclusion, the State Department of Education learns about it and leans on the people to scare them off. Several have told us they will be forced to leave the state. We ourselves been told to leave the state, that we would be hurt, that our house would be burned.

It may be that nothing we are doing will benefit our son, but we are determined to carry on this fight to insure that Arkansas cannot continue with the three Ds.

Our son has not had a chance for his free, appropriate public education because the school district, the State Department of Education, and the State Attorney General's office would rather spend their money on attorney fees than to educate David Bradley. They fear that other parents will come right behind us, demanding services for their children.

A doctor prescribed a laptop computer for David to use as a writing prosthesis. The school bought one that would not work right. We tried to get them to put it in working order. The district filed due

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DIARY OF A DAD UP AGAINST THE FOUR 'D'S

Continued from page 29

process against us to deny David the right to assistive technology. We had to go into that hearing without representation. The same hearing officer decided in favor of the school.

The superintendent of schools gave an interview to the newspaper calling us "radicals and troublemakers," and saying we are not welcome at any school. We are outnumbered and overwhelmed. Over the years we have appealed to our congressperson and senator to intercede for us. They have been unsuccessful. We have asked for help from the White House and from the Department of Education. We have asked for help from every disability group in the state, but no one here is willing to help. We have no money to hire expert witnesses, but the state attorney general's office has all the state's resources at its disposal.

November 1997. Our case went into federal court. Arkansas Assistant Attorney General Tim Humphries, representing the state, claimed in motions he filed that the state is immune under the Constitution's 11th Amendment. Federal Judge James Moody ruled that the state participates in federal programs voluntarily. If the state wants the federal money, it must abide by the federal rules. The state filed an appeal. Finding a way to fund our answer to this appeal has become nearly a full-time job in itself. In that same month we filed another due process complaint for an assistive technology evaluation. The district said that computers and software are for teachers, and admitted under oath that no student other than our son has ever had an assistive technology evaluation.

In response to our request to have David receive four hours of instruction per day at home, and that he be provided with the necessary assistive technology, the Assistant Attorney General for Arkansas argued that "no child has a fundamental right to education," and that "there is no law prohibiting Arkansas from discriminating against the disabled."

December 1997. Meeting with the Williford superintendent of schools. I told him I needed an agreement to provide my son with an appropriate education. If I could not get that, I would sue him personally. The superintendent did make an agreement, then reneged on it two days later and filed criminal charges against me for "terroristic" threatening and disorderly conduct. I was arrested and ordered to stay away from the school - this in spite of the fact that my son has only been able to attend school for the past 3 1/2 years when his mother or I went with him and stayed with him so he could come to us when he needed to.

A doctor we explained this to gave David a prescription for "homebound education." The school told us to "put the kid on the bus and send him to school like everyone else." We filed a request for due process. While waiting for the due process hearing, the school had me arrested for truancy.

At this time we started getting threats that David would be taken from us and placed in a juvenile detention facility for failure to attend school. For the next several months, Diane kept David in hiding in different locations while I tried to get our due process hearing expedited. The strain on them was enormous.

March 1998. The court found me not guilty of terroristic threatening and disorderly conduct, but guilty of my son's non-attendance at school. I was ordered to have my son in school Monday morning or go to jail for contempt of court.

On the following Monday we had our due process hearing at last. The hearing officer ordered a temporary placement in homebound instruction. The school was ordered to provide one hour of instruction four days a week at the local fire station. I filed a complaint with the U.S. Department of Education's Office for Civil Rights.

April 1998. Briefs in our case were filed in the Eighth Circuit Court. Arkansas is claiming, "No child has a constitutional right to an education."

August 1998. The school had hired a doctor to provide a "second opinion" evaluation of my son's need for homebound instruction. The due process hearing I requested eight months earlier now resumed. The school superintendent tried to ignore his own doctor's second opinion. The hearing officer, at the last hearing, had said that if the second doctor agreed with the first, "That's it." I reminded her. The hearing officer agreed she had made that statement and ordered the school to provide homebound instruction as recommended by the doctor the school had chosen.

At the following day's IEP meeting, the school agreed to hire a homebound teacher to work with David four hours a day, with Diane and I having final approval of the teacher hired. Other school concessions included that the curriculum would be designed to allow credits to be earned toward graduation, and that David would have a computer and software at last.

September 1998. The Eighth Circuit Court of Appeals in St. Louis, Missouri, heard the state's appeal of our case. Assistant Attorney General Tim Humphries argued that "No child has a fundamental right to education," and that "There is no law prohibiting Arkansas from discriminating against the disabled."

Attorneys Thomas K. Gilhool from the Public Interest Law Center of Philadelphia and Seth Galanter of the U.S. Department of Justice argued in support of our family and of IDEA.

November 1998. The school hired a special education teacher to work with David at our home three days per week, four hours per day. The teacher and school ignored the hearing officer's order requiring a computer and software. The teacher began instruction using textbooks from seventh grade.

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DIARY OF A DAD UP AGAINST THE FOUR 'D'S

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December 1998. We called an IEP meeting to demand the school provide the computer and software. The superintendent said they were unable to find appropriate software. We presented him with a prepared order form for software we had found. All that was left for him to do was write a check.

January 1999. The software and computer are in place. The teacher, however, has refused training about autism. "I know all I need to know," she says.

April 1999. Transition plan meeting. Here's where we were to discuss what we would like to do to prepare David for life after high school. We asked that a vocational rehabilitation (VR) staff person be present to help us figure out what would be available. VR personnel refused to attend until David's final semester in high school. So much for a transition plan at age 14. Once again, Arkansas ignores the law.

October 1999. The Eighth Circuit Court of Appeals issued an opinion in our case. Arkansas' claim of immunity was denied. The state must provide services to kids with disabilities.

February 2000. Still waiting for our day in court, we feel thoroughly betrayed by the writers of IDEA. To write such a law and give parents hope, then do nothing to enforce it is a cruel hoax to play on parents already suffering from the requirements of educating a child with disabilities. A report by the National Council on Disability (NCD) shows quite clearly that all states, not just Arkansas, have failed to implement IDEA, and that the U.S. Department of Education fails to hold states' accountable.

This entire system is analogous to writing a law requiring all cars to be driven no faster than 65 miles per hour, and providing all police departments with the money to buy advanced radar equipment to check speeds. Regulations are written, police officers are hired, equipment is purchased. Then, as the law plays out, passengers learn that they, and only they, are responsible for reporting and prosecuting any driver who exceeds the legal limit.

When we began this process, David was 12 and playing Teenage Mutant Ninja Turtles. Now he is 18, registering for Selective Service, and we are still years away from resolving his education.

Members of Congress, it is time to get real. Stop saying that IDEA requires schools to educate children with disabilities. It is untrue in Arkansas. According to the NCD report, it's not true in any state in the U.S. Don't give us hope with one hand and slap us down with the other.

We are truly sorry the system has failed David and us so badly. The Individuals with Disabilities Education Act was meant to assure parents of their children's right to Free Appropriate Public Education. We started on this quest for the elusive FAPE in 1995. IDEA assured us the purpose of the act was to resolve conflicts between parents and schools quickly but in our case, we have faced delay after delay.

Update: *January 2001*

Since last May a few things have happened. In August, as we prepared to start another disappointing year with the Williford School District, Diane, David and I talked it over and decided that we all wanted to find a way to allow David to graduate as soon as possible. When we met with the school district personnel to prepare the plan for the coming semester, we told them of our desire to have him finish school as soon as possible. We came up with a plan to send David to a local community college to take classes which would be considered for high school credits.

Once again it was left to us, the parents, to work out the details. We took David to the community college for testing. Based on the results of one test, David was only allowed to take remedial classes. The college personnel agreed, after about two weeks of on again, off again, to allow David to enroll for classes. Then we had to start all over to prove David had a disability that entitled him to be covered under Section 504 and ADA. Finally, after two very confusing weeks, David was allowed to start classes.

We discovered that even though we had moved from high school to community college, some things stayed the same. Administrative personnel made it very clear they really did not want him there. The administration agreed to provide accommodations for David, but as in high school, administrator's agreements proved to be worth very little. At one point when we invited an educator from out of state to come to observe David in class to help us draw up plans for the future, an administrator threw him out of the class. Fortunately, the students were older, more mature, and accepted David as an equal.

In December, David finished his classes at the community college and was awarded his high school diploma at the local fire department. I am still under a restraining order to stay away from the school. David is happy he does not have to have anything else to do with the Williford School District, as are his parents.

We are currently looking for a suitable college for David and looking for a job for me, so we can move from this backward state. We hope to move out of state as soon as possible.

Meanwhile, our lawsuit against the school district and state Department of Education continues at a snail's pace. In November, we filed a class action suit and consolidated this case with our original case. We will continue pursuing our lawsuits to try to help other children avoid the pain and anguish inflicted on David. We still will not be able to have our case heard in federal court until July 2001. But we will continue the fight, with the help of our friends at the Public Interest Law Center of Philadelphia.

The Bradley Family

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TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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